S. HRG. 110–841

HONORING FINAL WISHES: HOW TO RESPECT AMERICAN'S CHOICES AT THE END OF LIFE

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

ONE HUNDRED TENTH CONGRESS

SECOND SESSION

WASHINGTON, DC

SEPTEMBER 24, 2008

Serial No. 110–37

Printed for the use of the Special Committee on Aging

Available via the World Wide Web: http://www.gpoaccess.gov/congress/index.html
U.S. GOVERNMENT PRINTING OFFICE
49–769 PDF WASHINGTON : 2009

For sale by the Superintendent of Documents, U.S. Government Printing Office
Internet: bookstore.gpo.gov Phone: toll free (866) 512–1800; DC area (202) 512–1800
Fax: (202) 512–2250 Mail: Stop SSOP, Washington, DC 20402–0001

SPECIAL COMMITTEE ON AGING

HERB KOHL, Wisconsin, *Chairman*

RON WYDEN, Oregon
BLANCHE L. LINCOLN, Arkansas
EVAN BAYH, Indiana
THOMAS R. CARPER, Delaware
BILL NELSON, Florida
HILLARY RODHAM CLINTON, New York
KEN SALAZAR, Colorado
ROBERT P. CASEY, Jr., Pennsylvania
CLAIRE McCASKILL, Missouri
SHELDON WHITEHOUSE, Rhode Island

GORDON H. SMITH, Oregon
RICHARD SHELBY, Alabama
SUSAN COLLINS, Maine
MEL MARTINEZ, Florida
LARRY E. CRAIG, Idaho
ELIZABETH DOLE, North Carolina
NORM COLEMAN, Minnesota
DAVID VITTER, Louisiana
BOB CORKER, Tennessee
ARLEN SPECTER, Pennsylvania

DEBRA WHITMAN, *Majority Staff Director*
CATHERINE FINLEY, *Ranking Member Staff Director*

CONTENTS

PANEL I

APPENDIX

HONORING FINAL WISHES: HOW TO RESPECT AMERICANS' CHOICES AT THE END OF LIFE

WEDNESDAY, SEPTEMBER 24, 2008

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

The committee met, pursuant to notice, at 10:32 a.m. in room SD–562, Dirksen Senate Office Building, Hon. Herb Kohl (chairman of the committee) presiding.

Present: Senators Kohl [presiding], Wyden, Salazar, Whitehouse, Collins, and Rockefeller.

OPENING STATEMENT OF SENATOR HERB KOHL

The CHAIRMAN. Good morning to everyone. We will commence our hearing at this time. I would like to thank Senator Sheldon Whitehouse for holding today's hearing.

We are very pleased to have Senator Whitehouse as a member of this Committee and he is emerging as one of our leaders. Senator Whitehouse is tackling a very sensitive but extremely crucial issue this morning. We all thank him for that.

Today we will discuss end of life care, a topic which includes how to best treat patients at their most vulnerable stage in life. Most importantly we will discuss how to encourage advance planning about what kind of care people want for themselves at the end of their lives. At a time when shifting demographics are about to unleash an unprecedented number of older Americans, this Committee often focuses on planning for the foreseeable events ahead.

Through our work we urge our constituents to save for a secure retirement, make sure that they will have adequate health coverage and also to think about their future long term care needs. In terms of foreseeable events, perhaps it's a cliché, but the end of one's life is as inevitable as it comes. Advanced planning is meant to provide clarification at time that can be fraught with pain, confusion and sadness.

We will learn about how many Americans have acquired advanced directives. How likely the instructions are to be followed by our nation's health professions. In my own State of Wisconsin, we are engaged in promoting advanced directives on many levels all over our state.

For example, Gundersen Lutheran Medical Center in LaCrosse has streamlined advanced directives into their electronic medical records system. In Milwaukee, businesses have partnered to provide advanced planning material to their employees. Both of these efforts help to ensure that people get the care that they want at the end of their life.

Unfortunately we will hear from some of today's witnesses about the many barriers to advanced planning. I believe we can all agree that nothing should get in the way of providing comfort and solace to people at the end of their lives. Our hope is that this morning we will discover some policy solutions to promote the use of advanced directives within our nation's medical institutions.

I would like particularly to thank and welcome our witness from Wisconsin today, Joan Curran for being here today to testify on end of life care. Once again, I'd like to thank Senator Whitehouse for his leadership on this issue. At this time I will turn the hearing over to him.

Senator Whitehouse.

OPENING STATEMENT OF SENATOR SHELDON WHITEHOUSE

Senator WHITEHOUSE. Thank you, Chairman. Welcome to all our witnesses, many of whom have traveled a great distance to be here. I appreciate, very much, that you are here.

Now I first want to thank the Chairman for his encouragement of this hearing and for the wonderful cooperation we received from him and his staff in pulling all of this together. It has been vital to getting this done. I'm extremely grateful to him for his leadership of this Committee and for his leadership with respect to this issue.

I'm also delighted that my colleagues, Senator Wyden and Senator Salazar are here as well. I'm proud that they're here. I appreciate their attendance.

I consider the discussion that we're going to have today to be a vital one about choice and dignity at the end of life. This discussion can be uncomfortable, but anybody who has been there through the death of a loved one knows its importance.

It's a discussion, more than anything else, about free will, something we value very highly in this country. Making sure that people enjoy the exercise of their free will at the time of life where there is perhaps, the greatest premium on dignity.

Individuals at the end of life are vulnerable. Many are unable to communicate. Few are in a position to argue with a bureaucracy. We owe them the opportunity to make their wishes known and some certainty that the wishes made known will indeed be respected.

How much treatment do I want? Where do I want to be? How much pain do I wish to endure? These are wishes that should be honored.

It's particularly important to honor those wishes at the end of life because the ramifications of failing to do so are grim. Too many of us have witnessed a death taken over by machines and medicine turning the human being we love into a snarl of tubes and wires with humanity and dignity diminished. The late American political writer, Stuart Alsop, while he was dying, wrote "a dying man needs to die, as a sleepy man, needs to sleep, and there comes a time when it is wrong, as well as useless to resist." He was speaking from his own experience.

If someone chooses not to resist death, he or she should have the right to make that decision and to have it honored. So we face two broad policy questions that I hope this hearing will address.

First, how can we make sure that Americans carefully think about and communicate and document how they want to be treated at the end of life? Many people fail to complete advance directives because they believe they are difficult to execute or that they'll just be ignored. Many are reluctant to discuss death at all. Many think that completing a form is unnecessary because a loved one will make the right decisions for them.

Currently only between 18 and 30 percent of Americans have completed some type of advance directive. Acutely ill individuals do a little better, but only 35 percent of dialysis patients and 32 percent of COPD patients have advance directives. Even among terminally ill patients fewer than 50 percent have an "advanced directive" in their medical record.

The second policy question I hope this hearing will address is how can we help get those documented wishes actually translated into a plan of care with the provider? How can we make sure, for example that EMS workers don't resuscitate a patient against patients' documented wishes? That doctors can comfortably provide adequate pain medication to patients in need. Or that patients can receive palliative care wherever they are.

Currently roughly 70 percent of physicians whose patients have advance directives do not know about them. This is a fundamental disconnect. Particularly troubling in light of the fact that physicians don't accurately predict their patients' preferences all the time, indeed about 65 percent success rate. Fortunately we have invited some superb individuals to help us wade through these questions from a variety of perspectives.

I think what we'll do is have all the witnesses testify, and then we'll have a question and answer session. I'd ask the witnesses to keep their testimony to 5 minutes. I'll give a little signal when it's getting there, so that we have more time for a more general discussion.

One witness is Joseph O'Connor, who has been the Chair of the American Bar Association's Commission on Law and Aging since 2005. The Commission has been involved in end of life legal research and implementation of appropriate end of life policies for the past 29 years. Mr. O'Connor is a partner in the law firm of Bunger and Robertson in Bloomington, IN. He has served the Indiana State Bar Association in various capacities including as its President.

Dr. Diane Meier is the Director for the Center to Advance Palliative Care, a national organization devoted to increasing the number and quality of palliative care programs in the United States. She's also Director of the Lilian Benjamin Hertzberg Palliative Care Institute and Professor of Geriatrics, Internal Medicine and Medical Ethics at the Mount Sinai School of Medicine in New York City. She is the principle investigator of an NCI funded, 5 year, multisite study on the outcomes of hospital palliative care services in cancer patients. Just yesterday, Dr. Meier received a MacArthur Foundation Fellowship, the so-called "genius grant", which she hopes will help her with her children. [Laughter.]

For her leadership in innovation in promoting high quality palliative care. Congratulations, Dr. Meier.

Dr. Joan Teno, a friend from Rhode Island, is a Professor of Community Health and Medicine, an Associate Director of the Center for Gerontology and Health Care Research at the Brown University Medical School. She's a Health Services Researcher, Hospice Medical Director and Board Certified Internist with added qualification in geriatrics and palliative medicine. Dr. Teno has served on numerous advisory panels including the Institute of Medicine, World Health Organization, American Bar Association and as grant peer reviewer for the National Institutes of Health. She is also an Associate Medical Director at Home and Hospice Care of Rhode Island.

Drew Edmondson serves as the Attorney General of Oklahoma. I had the honor of serving as Attorney General of Rhode Island while Drew was Attorney General of Oklahoma. He was elected by his peers to be the head of the National Association of Attorneys General and as the President of that Association made high quality, end of life care a priority.

Thanks to advocacy from his office, the past three Oklahoma Governors have all endorsed and participated in a state wide, palliative care week aimed at raising awareness about end of life decisionmaking. Attorney General Edmondson has also convened legal experts, health care providers and community leaders to form the Oklahoma Attorney General's Task Force on end of life health care, which continues to study this issue and advocate for the forums.

Finally, Dr. Patricia Bomba is the Vice President and Medical Director of Geriatrics for Excellus Health Plan Incorporated and subsidiaries of the Lifetime Health Care companies. In her current role, she serves as a Geriatric Consultant on projects and program development affecting seniors. She's a nationally recognized palliative care and end of life expert who designs and oversees the implementation of community projects.

She's New York State's representative on the National POLST Paradigm Task Force, a multi-state collaborative. She served as a New York State delegate to the White House Conference on Aging, and is a member of the review Committee of the National Quality Forums framework and preferred practices for palliative and hospice care quality projects.

So we have a brilliant group of witnesses and before we go to them for their statements I would ask my colleagues, Senator Wyden of Oregon and Senator Salazar of Colorado if they would like to share a few words with us.

OPENING STATEMENT OF SENATOR RON WYDEN

Senator WYDEN. Thank you, Mr. Chairman. I commend you, Chairman Whitehouse for particularly scheduling this session. As we go into the national reform debate in the next session of Congress, I think it is fair to say that you cannot get that topic right unless you expand options for sensible, end of life care.

So I commend you, Chairman Whitehouse and also Chairman Kohl for your leadership. You have guided us throughout this session into a host of important issues. We've been particularly appreciative of the fact that you've allowed members of the Committee to chair hearings. Senator Whitehouse has been a real addition to the U.S. Senate in the health debate, very pleased that you're staking out this question.

I think it's fair to start this discussion with a little bit of history because regrettably on the end of life issue the U.S. Senate has had to spend a lot of time in recent years blocking ill advised ideas. In particular two areas I have been involved in. I went to the floor of the U.S. Senate twice to block the original Terry Schiavo legislation.

I think we all remember the tragedy of that story, a severely brain damaged, Florida woman. A measure was, in effect, proposed authorizing that that case be removed to the Federal courts. It would have set a precedent in effect for the U.S. Congress to intervene in family tragedies across the land. I objected until the measure was redone to allow Federal court intervention just in the Schiavo case. Of course we all remember the tragedy of that woman dying shortly afterwards.

We had much the same thing in the debate about Oregon's Death with Dignity law, a law that I didn't even vote for at the time. The measure passed in the House of Representatives to undermine the Oregon law. There was a sense that the Senate would simply go along with the House and throw the Oregon law in the trash can. I objected to that too. The Oregon law remains on the books.

So I noted Chairman Whitehouse's fine statement of Dr. Meier that you're being recognized for you genius. I hope some of that starts to apply in the Congressional examination of end of life issues. Because, regrettably in the past there have been a fair amount of ill advised proposals.

What I think the part of what needs to be done in the future end of life care, what we try to do in the Healthy Americans Act, a bill with 16 sponsors, eight Democrats and eight Republicans, is to try to get at the area all Americans seem to support and that is creating more options for families and our loved ones in terms of end of life. Chairman Whitehouse touched on the advanced directives effort. That is something we encourage in the Healthy Americans Act.

We feel very strongly that families ought to have access to 24/7 assistance in terms of end of life options. It seems so often the crisis about end of life care takes place on a Sunday night and there is no doctor or nurse available. People have nowhere to turn.

So to have those options is something we've included in the Healthy Americans Act. Senator Rockefeller, who serves on the Finance Committee with Senator Salazar and I, feels very strongly about creating those options. I think, this is something the American people feel strongly about as well.

Finally with respect to hospice care. My goodness, we should all agree on expanding more options for hospice care. One that I felt strongly about that we put in the Healthy Americans Act is right now, the Federal Government basically says you've got to give up the prospect of curative care in order to get the Hospice benefit, which just seems inhumane and contrary to all of what you all as witnesses have been advocating for.

Let's give families as many options as we can. So we make clear in the Healthy Americans Act that you do not have to give up the prospect of curative care in order to get the Hospice benefits. If we can steer clear with your genius, Dr. Meier and others, of some of these ill advised approaches that we've had in recent years and go to where I think the American people want us to go which is a consensus.

That let's give them more options for them to choose from—not for government to dictate but options for them to choose from. With the leadership of Chairman Whitehouse and good sessions like this, we can make good progress in this area. Particularly make sure that next year, when we move ahead on health reform we finally get end of life care right and create the kinds of options that all of you and others are advocating for. So, Mr. Chairman, I thank you and particularly for your leadership.

Senator WHITEHOUSE. I thank you, Senator Wyden. As he indicated, Senator Wyden's Healthy Americans Act is, probably, is the leading bipartisan healthcare bill in the Senate right now. It's thanks to energy and diligence and foresight that it has gotten as far as it has.

I'm now pleased to call on Attorney General and now Senator, Ken Salazar, part of the merry band of Attorneys General who served with Attorney General Edmondson.

Senator Salazar.

OPENING STATEMENT OF SENATOR KEN SALAZAR

Senator SALAZAR. Thank you very much, Senator Sheldon, Whitehouse and Attorney General Edmondson, welcome to the U.S. Senate. Someday you may be joining us here and hopefully you'll be on the Aging Committee and on the Finance Committee and on the Judiciary Committee. There's some wonderful Committees here.

To Chairman Kohl, thank you so much as well for focusing in on this issue. We have been involved in the Finance Committee over the last year on trying to figure out what we ought to do with healthcare reform. I think a lot of us can describe the problem, each of us in our own states, each of us doing something to try to put a greater level of understanding on the issue of healthcare.

I know Senator Wyden has been the lead proponent of bringing together Republicans and Democrats to focus in on the issue in a very effective and successful way. Senator Whitehouse, himself, has put together a bipartisan group which he has met with regularly to try to address the issues of healthcare. Senator Kohl, I can tell you that without your leadership on this Committee there would be issues that I think would be overlooked.

So, today in particular, as we look at end of life issues and the complexity around those end of life issues, it seems to me that the inescapable conclusion that I have is that we need to make sure that this is part of our dealing with the future of healthcare here in America. As Senator Whitehouse stated, it is an issue that affects each and every one of us. We've seen it happen in our own families and we've seen it happen with other people.

It was under the leadership of Attorney General Edmondson, as the President of the National Association of Attorneys General that we put together, not only a national summit, but summits around the country to try to deal with this issue. I think that there is no limitation on the amount of attention that we need to bring to this issue, because it's still an issue that for whatever reason, isn't put on the radar screen of America in the way that it should. Hearing Senator Whitehouse talk about statistics with respect to advanced directives and the fact that less than a third of the people in America actually have advanced directives.

Then if you analyze the number of doctors who've actually read the advanced directives. Know that there's an "advanced directive" there for a patient than it's really a small percentage really of people who are guiding their own destiny. In most cases at a time when they can't even have the consciousness to do it.

So this the right issue. It's the right issue for moral reasons, for ethical reasons, for legal reasons, for cost reasons and a whole host of other issues. So I just appreciate the quality of this panel. Again it's an honor for us, Drew, to have you here as our comrade in arms as Attorney General for Sheldon and for me to be able to have you here as one of the witnesses in this hearing. We really, really appreciate it.

Thank you very much, Mr. Chairman.

Senator WHITEHOUSE. Thank you, Senator Salazar.

Senator SALAZAR. If you're really good Drew Edmondson, you do what Sheldon Whitehouse does which is, you know, he hasn't been here that long. He's already chairing a Committee. [Laughter.]

Really good.

Senator WHITEHOUSE. Alert viewers will have noticed that one of the witnesses was not introduced when I went through the panel. That is because she hails from the home state of The Chairman. So our last act before we get to the witnesses is to invite Chairman Kohl to introduce Joan Curran of Wisconsin.

The Chairman. Thank you, Senator Whitehouse. As he said, I do have the honor and the distinct pleasure to introduce Joan Curran who's from LaCrosse, WI. She has graciously agreed to share her story with us today.

Ms. Curran has both professional and personal experience with end of life planning. Currently she is the Chief of Government Relations in External Affairs at Gundersen Lutheran Medical Center in LaCrosse. Gundersen Lutheran has successfully implemented a very good system for end of life planning. Indeed has one of the best systems throughout our country. Ms. Curran will share her personal experiences today.

With that, we turn the microphone over to you, Ms. Curran.

STATEMENT OF JOAN CURRAN, EXECUTIVE DIRECTOR—EXTERNAL AFFAIRS, GUNDERSEN LUTHERAN MEDICAL CENTER, LACROSSE, WI

Ms. CURRAN. Chairman Kohl, Senator Smith, Senator Whitehouse, members of the Special Committee on Aging, thank you for giving me the chance to talk with you about advanced care planning today. For the past 26 years I've worked for Gundersen Lutheran. An integrated health system headquartered in LaCrosse, WI with clinics and healthcare services in Wisconsin, Minnesota and Iowa.

For more than 20 years ago the entire LaCrosse community committed to an innovative model of the advanced care directives. They made sure it went beyond just filling out paperwork and legal documents. They made sure that the "advanced directive" was in every person's medical record, where and when it was needed. They made sure that medical professionals had the training to know how to comply with the patients' wishes.

The system was designed by healthcare professionals and was implemented even before there were electronic medical records. As I speak to you today it's not only as an employee of the Medical Center who has lead the Nation in advanced care planning. I'm here today to tell my personal stories in hopes that you'll be showing how advanced care planning is more than just filling out the paperwork.

In 1989 my friend Annette experienced headaches so severe that she went to the emergency room on a Sunday afternoon. That day she was diagnosed with a brain tumor. She was 28 years old.

Annette went through surgery that week to determine the severity of the tumor. She and I were both stunned when the neurosurgeon told us that it was a Grade 4 out of Grade 5 malignancy. Although the surgery was successful, she was given 6 months to live, perhaps a year if they could slow the growth with radiation treatment.

The radiation started a few weeks later. During the next weeks we were both focused on dealing with the treatments, side effects and how frightening this was for both of us. The hospital chaplain was the first individual to discuss with Annette whether she wanted to talk about her treatment in the event she could not speak for herself.

At the time I remember being upset that anyone would want to discuss such a sensitive subject at such a fragile and emotional time. To my surprise, she was relieved to have the topic on the table. With the chaplain and later her physician, we went over her decisions.

Annette asked me to be the person who made sure her treatment choices were honored. I wasn't sure I could do it. With the help of an attorney in the pastoral care department at the hospital, we secured the needed documentation for healthcare power of attorney, as well as power of attorney. Through those documents we codified what care Annette wanted as her illness progressed.

But more importantly through the discussions that were facilitated as we filled out those documents, I became very comfortable and fully understood what she wanted and why it was important to her. These discussions allowed me and her loved ones to cope with what was happening to Annette. We were so fortunate that the medical center and staff were supportive of her decisions, too. Because of this we were certain everyone was on the same page and her treatment plan reflected her wishes.

We also became more knowledgeable about the legal implications and limitations of the existing system. For example, we found out that emergency care and her acute care and hospital care were not coordinated by any uniform standard. So we taped a copy of Annette's advanced directives and my healthcare power of attorney to her bed and to the door of our house in case an emergency happened. That way, even in an emergency Annette would receive the care she wanted and she would not receive care she didn't want.

We both carried paper copies with us in the event the unexpected happened.

Two years after Annette's original diagnosis, she no longer had the ability to communicate. Her treatment wishes were well established in her care plan and any treatment options considered those wishes. I was with her when she died on Christmas Day 1991.

As she had chosen, she received only the care that she wanted. It proved to be the greatest gift I could have ever given her. That in itself gave me comfort in the months following her death.

Before I came to Washington today, I reviewed Annette's "advanced directive" written nearly 20 years ago. On it was a handwritten note from Annette that I had forgotten. It read, "I would like Joan to be my healthcare agent because she's been a great friend to me for many, many years. We've talked an agreed that she would make all my decisions for me." This "advanced directive," then and now, allowed all of us and Annette's loved ones to move beyond her death and celebrate her life.

My second experience with end of life planning was a very different situation. With Annette, she was young and her illness lasted for two and a half years. Several years later my 84 year old Dad died very suddenly and unexpectedly.

One afternoon long before dad got sick, Mom and Dad let my siblings and I know that they had completed advanced directives. Throughout the discussion when one of us would say, "Dad, you can't mean that." He would let us know that indeed that is what he meant. My mother wanted to make sure that everyone understood what they wanted so there would be no disputes.

By the end of the conversation, we were clear on who would be making the decisions. Each of us had a copy of their wishes. What proved to be the most important was that we all understood what those written words meant.

On December 18, 2004, my Dad was taken to the emergency room. Dad was diagnosed with bleeding in his brain and was transferred from the local emergency room in Minnesota to nearby Gundersen Lutheran Medical Center in Wisconsin. His "advanced directive" went with him.

Unlike my experience in 1989, by 2004 Gundersen had incorporated advanced care planning into their electronic medical record system which made it easy for information to be available to any medical professional treating my Dad. That Saturday, Dad was making good progress and he was anxious to go home. Our physician wanted to keep him one more night.

Fifteen minutes after I left the hospital, I got a call that Dad was in trouble. As my Dad was being wheeled down the hallway to undergo a CT scan the last words to my sister, from him, were, "No more." The doctor explained to us that Dad would no longer be able to talk, to walk or to feed himself. Within a short period of time he would need life support to help him breathe.

The doctor gave us some treatment options, but it was clear that Dad would never regain functionality. I remember asking my Mom if she understood what the doctor had said and if she needed him to repeat anything or if she had any questions. She confidently nodded her head and said to him, "Thank you, doctor, your work is done here. He's in God's hands now." It was just after midnight.

As a family we're all comfortable with the way my Dad chose to die. We've never had to wonder whether it was the right thing to not seek additional treatment or if we made the right decisions. Since then we've been able to spend time helping our Mom, enjoying what time we have left with her.

I urge this Committee to give the rest of the country what patients in LaCrosse, WI have had access to for many years, a system that allows people to make their wishes known and a healthcare organization that value and respect those choices. By expanding Gundersen's end of life care model across the nation, healthcare systems will engage their patients in the right discussions, developing the mechanisms to incorporate those wishes into their treatment plans. Please take a minute to read the information at the end of my written testimony which outlines our Gundersen Lutheran end of life care system. The work and proven results of our system, our transforming end of life care to increase continuity of care, quality of care and respect for patients' wishes while lowering the cost and reducing overall utilization of the healthcare system.

As you move forward my strongest recommendation is that you would remove barriers and create incentives to expand this successful end of life care planning nationwide. Any policy or regulations regarding advanced care planning should incorporate six principles. They are briefly.

One, healthcare professionals should have all adults understand and document their end of life care goals and preferences, as well as designate an end of life care decisionmaker.

Two, there should be a process to convert treatment goals and preferences into medical orders to ensure information is transferable and honored.

Three, universal implementation of electronic medical records and internet-based personal health records shall include and integrate timely information relevant to the patient's advance directives.

Four, if no advance directive exists at the time of need any authentic expression of an individual's goals, values or wishes with respect to healthcare should be honored.

Five, Federal support for research, education and expansion of the best practice relating to the quality and continuity of care related to advanced directives and the end of life.

Six, Medicare would reimburse organizations at a higher level if certain advanced care planning outcomes were met.

For example, if 85 percent or more of the adult decedents had a written advance directive found in the medical record at the site of care. The wishes expressed in the document were consistent with the treatment provided rather than reimbursing for a specific event. Payment would be hinged on outcomes that meet performance benchmarks.

On behalf of my Dad and my friend, Annette, I ask you to give families and loved ones the opportunity to experience this gift of love and give the medical community the ability to fulfill the wishes of their patients. Thank you for this opportunity to speak to you today about this important issue.

[The prepared statement of Ms. Curran follows:]

Gundersen
Lutheran

Testimony Provided To:

U.S. Senate Special Committee on Aging
Hearing on Advance Directives and End of Life Care

September 24, 2008

By:

Joan Curran, MBA
Resident of La Crosse, Wisconsin
Gundersen Lutheran Health System
www.gundluth.org
Direct: (608) 775-4347
JLCurran@gundluth.org

Chairman Kohl, Senator Smith, Senator Whitehouse and the members of the Special Committee on Aging, thank you for giving me the chance to talk with you about advance care planning today.

For the past 30 years, I've worked in healthcare. The last 26 years I have held a variety of positions with Gundersen Lutheran, and integrated health care system headquartered in La Crosse, Wisconsin with clinics and healthcare services in Wisconsin, Minnesota and Iowa.

Dying is an uncomfortable subject to discuss. Most of us don't even want to think about it. But when the healthcare we receive at the end of life is patient-centered, coordinated and proportional to the patient's wishes – never more and never less – the healthcare process of dying results in a higher quality care delivered at a lower cost.

As I speak to you today, it's not only as an employee of the medical center who has led the nation in advance care planning. I am here today to tell my personal story in hopes of showing how advance care planning is more than just about filling out the paperwork. Today is about what it means to take care of loved ones when they are sick and how we choose as individuals to be taken care of when we are sick. Today is about supporting you in your work to make sure that the choices of each patient are honored and respected by the healthcare facility caring for them at the end of their life.

In 1986 Gundersen began to work on an advance care planning model. In 1991, the entire La Crosse community built on this model by committing to an innovative system of advance care directives. They

External Affairs Department 1900 South Avenue, GB2-004 La Crosse, WI 54601
Phone: 800-362-9567 or 608-782-7300 Fax: 608-775-6225

made sure it went beyond just filling out paperwork or a legal document. They made sure the advance directive was in every person's medical record where and when it was needed. And they made sure medical professionals had the training to know how to comply with a patient's wishes. The system was designed by health care professionals and was implemented when there were no electronic medical records.

In 1989 I knew nothing about end of life planning and advance directives. I also didn't know that my close friend would be diagnosed with a terminal brain tumor. I didn't know that this experience would prepare me for my father's death many years later. Both experiences taught me that end of life planning is an act of love and courage. I offer the story of two very different deaths in hopes that you will see the value advance care planning has as part of the U.S. healthcare system.

In May 1989 my friend Annette experienced headaches so severe that she went to the emergency room on a Sunday afternoon. That day, she was diagnosed with a brain tumor. She was just 28 years old. Annette went through surgery that week to determine the severity of the tumor. She and I were both stunned when the neurosurgeon told us the tumor was a Grade IV out of V malignancy. Although the surgery was successful, she was given six months to live - perhaps a year if they could slow the growth with radiation treatment. The radiation started a few weeks later and during the next weeks we both focused on dealing with treatments, side effects and how frightening this all was for both of us.

The hospital chaplain was the first individual to discuss with Annette whether she wanted to talk about her treatment in the event that she could not speak for herself. At the time, I remember being upset that anyone would ask her to discuss such a sensitive subject at such a fragile, emotional time. To my surprise she was relieved to have the topic on the table. With the chaplain, and later her physician, we went over her decisions. Annette asked me to be the person who made sure her treatment choices were honored. I wasn't sure I could do it.

With the help of an attorney and the pastoral care department at the hospital, we secured the needed documentation for health care power of attorney as well as power of attorney. Before I came to Washington today, I reviewed Annette's advance directive – written nearly 20 years ago – on it there was a handwritten note from Annette that I had forgotten. It read "I would like Joan to be my 'health care agent' because she's been a great friend to me for many, many years. We've talked and agreed that she would make all my decisions for me." Through those documents we codified what care Annette wanted as her illness progressed. But more importantly, through the discussions that were facilitated as we filled out these documents, I became very comfortable and fully understood what she wanted and why it was important to her. Those discussions allowed me and her loved one's to cope with what was happening to Annette. We were so fortunate that the medical center and the staff there were supportive of her decisions, too. Because of this, we were certain that everyone was one the same page and her treatment plan reflected her wishes.

We also became more knowledgeable about the legal implications and limitations of the existing system. For example, we found out that emergency care and her acute and hospital care were not coordinated by any uniform standard. So we taped a copy of Annette's advance directives and my healthcare power of attorney to her bed and on the door of our house in case an emergency happened. That way, even in an emergency, Annette would receive the care she wanted, and she would not receive care she didn't want. We both carried paper copies with us in the even the unexpected happened.

Two years after Annette's original diagnosis, she no longer had the ability to communicate. Her treatment wishes were well established in her care plan, and any treatment options considered those wishes. I was with her when she died on Christmas Day 1991. As she had chosen, she received only the care that she wanted. It proved to be the greatest gift that I could have ever given her and that in and of itself gave me comfort in the months following her death. This advance directive – then and now – allowed all of Annette's loved ones to move beyond her death and celebrate her life.

The experience with Annette changed how I viewed end of life planning and I completed my own advance directives. I have shared them with my husband, my extended family, and my child when he became an adult. From time to time we have a check-in discussion and it proves to be a good avenue to share other messages of support and appreciation.

My second experience with end of life planning was a very different situation. With Annette, she was young and her illness lasted for two and a half years. Several years later, my siblings and I were confronted with the mortality of our own parents – specifically, my dad who was 84 but died very suddenly and unexpectedly in 2004.

My Dad knew how he wanted to live and his choices reflected his values. At the age of 13 he quit school to take care of 4 younger brothers and help on the farm after his mother died. He served in WWII and came home, married my mother, and had seven children. After a few years of selling and trucking produce, he opened his own business which he operated until he retired. He and my mom were devout Catholics, shared good health and were active people.

One unexpected afternoon, my Dad let my siblings and I know that he and my Mom wanted to talk with us about how they wanted to be cared for in the event that they could not speak for each other or themselves. Throughout the discussion when one of us would say, "Dad, you can't mean that..." he would let us know that indeed was what he meant. My mother wanted to make sure everyone understood what they wanted so there would be no disputes. By the end of the conversation, we were clear on who would be making the decisions and each of us had a copy of their wishes. What proved to be most important was that we all understood what those written words meant.

On December 18th, 2004 my sister called me to let me know Dad had been taken to the emergency room. Just the day before when we had talked he was fine.

When Dad was diagnosed with bleeding in his brain he was transferred from the local emergency room in Minnesota to nearby Gundersen Lutheran Medical Center in Wisconsin. The medical staffs were made aware that he had an advance care plan in place and all the steps were taken to ensure that any treatment would incorporate those wishes. By 2004, Gundersen Lutheran had incorporated advance care planning into their electronic medical record allowing for information to be easily communicated to any health care practitioner. That Saturday was a blur but by the end of the day the bleeding had stopped. Although he had some weakness, the prognosis was good and it looked like he would be discharged on Sunday or Monday.

On Sunday he was making good progress and he was anxious to go home. Our physician wanted to keep him one more night. About 6:30 p.m. I went home to shower and change and planned to spend the night with my Dad. As I left the hospital I remember letting the nurse know that I would be back in 30 minutes and that he was doing fine and asked her to call me if he needed anything that I could bring from home. At that time I lived less than 5 minutes from the medical center and so I was surprised when 10 minutes after I got home the hospital called and said that my Dad was in trouble. I called my sister who lives close and told her what had happened.

By the time I got back to the hospital my Dad had lost feeling in his right side, so the doctors wanted to take him down for a CT scan to determine what was happening. My sister arrived just as they were wheeling him down and reassured him that we would be there when he got back and that my Mom and brother would be there soon. Dad's last words to my sister were "no more."

By the time Dad was back from his test, the physician sat down with us to explain Dad had experienced a significant bleed and he would no longer be able to talk, walk or feed himself. Within a short period of time he would need life support as his breathing would be compromised. He provided us with some treatment options, but it was clear that my Dad would never regain functionality. I remember asking my mom if she understood what the doctor had said and if she needed him to repeat anything or had any questions. She confidently nodded her head and said to him. "Thank you doctor, your work is done here. He is in God's hands now." It was just after midnight.

From that point on the support we received centered around making my Dad comfortable and helping us adjust knowing that he only had a short time left. The medical and support staff were all respectful of our decisions and helped us through these final hours. He received his last rights, our family surrounded his bed, and my mom, his wife of over 50 years, was holding his hand when he died just 2 days after his unexpected Emergency Room visit. As a family, we've never had to wonder whether it was the right thing to not seek additional treatment or if we made the right decisions. As a family, we're all comfortable with the way that dad chose to die. Since, we've been able to spend our time helping mom and enjoying what time we have left with her.

Closing Remarks:

I urge this Committee to give the rest of the country what patients in La Crosse, Wisconsin have had access to for many years; a system that allows people to make their wishes known and healthcare organizations that value and respect those choices.

By expanding Gundersen's end of life care model across the nation, you will be providing families and loved ones with support to have one of the most important conversations of their life. This will allow families to come together, rather than be torn apart, when they need each other most. Through your efforts healthcare systems will engage their patients in the right discussions, developing the mechanisms to incorporate those wishes into treatment plans. On behalf of my father and my friend Annette, I ask you to give others the opportunity to experience this gift of love and give the medical community the ability to fulfill the wishes of their patients.

I wanted to share my personal story today, but please take a minute to read the information in the attached document, which outlines Gundersen Lutheran's end of life care system. As you will see, the cost of dying at Gundersen Lutheran is about $18,000 and family satisfaction is extremely high. In comparison, the national average cost of dying is more than $25,000, and at many of the nation's leading healthcare organizations the cost is as high as $31,000 and $58,000.

As you move forward, my strongest recommendation to you is to remove barriers and create incentives to expand this successful end of life care model nationwide. The work and proven results of Gundersen Lutheran's experience are transforming end of life care to increase continuity of care, quality of care, and respect for patients' wishes, while lowering the cost of care and reducing over-utilization of the healthcare system. This model can be implemented across the nation in every setting whether the medical record is paper or electronic. In addition, we encourage that the six principles outlined in our written testimony be incorporated into any policy or regulation related to advance care planning:

1. Health care professionals should help all adults understand and document their end-of-life care goals and preferences as well as designate an end-of-life care decision-maker.
2. There should be a process to convert treatment goals and preferences into medical orders to ensure information is transferable and honored.
3. Universal implementation of electronic medical records and internet-based personal health records shall include and integrate timely information relevant to the patient's advance directive.
4. If no advance directive exists at the time of need, any authentic expression of an individual's goals, values or wishes with respect to healthcare should be honored.
5. Federal support for research, education, and expansion of best practices relating to the quality and continuity of care related to advance directives and the end of life.
6. Medicare would reimburse organizations at a higher level if certain advance care planning outcomes are met. For example, if 85% or more adult decedents had a written advance directive found in the medical record at the site of care, and the wishes expressed in the document were consistent with the treatment provided. Rather that reimbursing for a specific event, payment would be hinged on outcomes that meet performance benchmarks.

Thank you for this opportunity to speak to you today about this important issue.

Gundersen
Lutheran

Gundersen
Lutheran

Policy and Regulatory Principles for Advance Care Planning

1) Health care professionals should encourage and offer assistance to all adults, helping individuals to understand and document their end-of-life care goals and preferences as well as designate an end-of-life care decision-maker.

2) Health care professionals should have a process to convert treatment goals and preferences of persons with life-limiting illness into medical orders (e.g. the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Initiative) to ensure that information is transferable and applied across all care settings.

3) In the absence of a validly executed advance directive, any authentic expression of an individual's goals, values, or wishes with respect to health care should be honored.

4) Universal implementation of electronic medical records and internet-based personal health records shall prominently include and integrate timely information about patient proxy designations, care goals and preferences, and medical orders for life-sustaining treatment. This information should be stored within the electronic health record system of the individual's community-based hospital, not a national data warehouse.

5) The federal government should support research, education, and development of best practices relating to the quality and continuity of care planning and care implementation for persons with life-limiting illnesses across care settings.

6) Medicare would reimburse organizations at a higher level if certain advance care planning outcomes are met. For example, if 85% or more adult decedents had a written advance directive found in the medical record at the site of care, and the wishes expressed in the document were consistent with the treatment provided. Rather that reimbursing for a specific event, payment would be hinged on outcomes that meet performance benchmarks.

External Affairs Department 1900 South Avenue, GB2-004 La Crosse, WI 54601
Phone: 800-362-9567 or 608-782-7300 Fax: 608-775-6225

Transforming Healthcare at the End of Life

Gundersen Lutheran.
HEALTH SYSTEM

Gundersen Lutheran Health System is leading the nation with an innovative end-of-life program that provides the right healthcare to patients in the end stages of their lives. Our system increases continuity of care, quality of life and respect for the patient's wishes, while lowering the cost of care and reducing over-utilization of the healthcare system.

The system is based on well-established, existing programs at Gundersen Lutheran, including:

- A community-wide advance directives program which makes advance directives available to every person, ensures they are available wherever and whenever patients need them and ensures healthcare professionals comply with the patient's treatment choices.
- Hospice and palliative care programs, which assist patients with advanced diseases through the physical, psychosocial and spiritual aspects of aging and dying.
- Coordination of these services by use of electronic medical records, which can be accessed by all medical professionals in the health system and region at all sites of care.

The future of healthcare

Gundersen Lutheran's approach to advance directives has led to the development of a model of care we're calling Late Life Primary Care, which encompasses advance directives, palliative care and hospice. When all of these programs work together, the Late Life Primary Care approach can save between $3,000 and $6,000 per patient, per year. Gundersen Lutheran has presented the Late Life Primary Care concept to the Centers for Medicare and Medicaid Services (CMS) as a model to change the way end-of-life care is delivered on a national scale. The entire proposal is available for review.

Cost of Care in the Last Two Years of Life*

Hospital	Reimbursement per Deceased Patient (2 -year total)	Reimbursement Per Day	Hospital Days per Deceased Patient
Gundersen Lutheran	$18,359	$1,355	13.5
Marshfield/St. Joseph's	$23,249	$1,126	20.6
U.S. National Average	$25,860	$1,096	23.6
University of Wisconsin	$28,827	$1,462	19.7
Cleveland Clinic	$31,252	$1,307	23.9
Mayo Clinic	$31,816	$1,497	21.3
UCLA	$58,557	$1,871	31.3

**Based on 2007 Dartmouth Atlas Study Methodology. The Dartmouth Atlas methodology examines hospital inpatient care for the last two years of a Medicare patient's life.*

External Affairs Department 1900 South Avenue, GB2-004 La Crosse, WI 54601
Phone: 800-362-9567 or 608-782-7300 Fax: 608-775-6225

Advance Directives

Gundersen Lutheran's advance directives program is a proven model for improved end-of-life planning and decision making. What makes this program successful is a comprehensive, systematic approach that includes three key components:

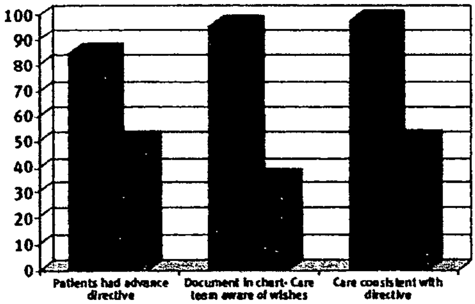
- Community approach: Systems have been set up to foster conversations about advance directives in the community using medical and community resources. For example, discussions about advance directives have been built into Gundersen Lutheran's hospital admissions process, and Gundersen Lutheran has trained advance care planning facilitators available to answer questions for patients at any time.
- Availability of information as a standard practice: This model allows advance directives to be available in patients' medical records so the directives are available wherever patients are and whenever they need them.
- Professional education: Having an advance directive is not enough. Healthcare professionals must also comply with it. Educating providers about advance directives has led to a high level of provider compliance with patients' treatment choices.

The program's focus on a systematic approach to advance directives has resulted in a high prevalence of planning by the time of death. End-of-life care plans are almost always available at the site of care, and there's consistency between the plans and actual decisions at the end of life. Studies at Gundersen Lutheran have shown patients with advance directives used about $2,000 less in physician and hospital services in the last six months of life—the time period when most medical care expenses are incurred.

Results of our program

Since its inception in 1986, the Gundersen Lutheran advance directives system has had a significant impact on end-of-life planning and decision making. Data released by Gundersen Lutheran in 2008 show of all adult residents who died in La Crosse County over a six month period under the care of a physician (408), 90 percent had a written advance directive and all of these documents were found in the medical record where the patient died. Of these patients, 96 percent had an advance directive or Physician Order for Life-Sustaining Treatment (POLST) form in their medical records. These results have been sustained over a 12-year period.

Results of our program compared to national averages



National Information: Research in Action, AHRQ, Issue #12, March 2003

La Crossse Information: Hammes BJ, Rooney B. "Death and End-of-Life Planning in One Midwestern Community." *Archives of Internal Medicine.* 1998;158:383-390

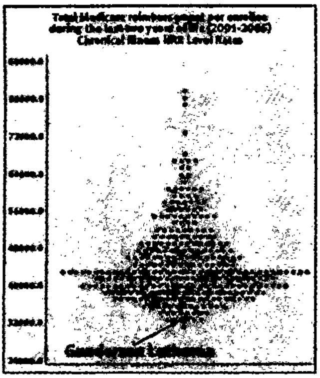
An internationally recognized program

Gundersen Lutheran's model for advance directives led to the development of the Gundersen Lutheran Respecting Choices® program. Respecting Choices has been implemented in more than 55 organizations or groups in the United States, is gradually becoming a model for end-of-life care in Australia under the funding of the Australian Ministry of Health, is being implemented in two large health authorities in Canada and is being adapted for use in Germany to increase the use, quality and validity of advance directives in nursing homes.

Advance Directives and the Electronic Medical Record

A novel, sophisticated advance care planning electronic application has been embedded into Gundersen Lutheran's electronic medical record. That means a patient's advance directive is available for healthcare providers at all sites of care throughout the Gundersen Lutheran Health System. What is more, the advance care planning electronic application goes beyond the advance directive. It brings together all advance care planning practices at Gundersen Lutheran into one electronic system including:

- Guides practitioners through initiating and updating advance care planning conversations
- Allows the clinician to document that the patient was given advance care planning education
- Allows physicians to dictate advance care planning notes as part of their routine dictation and easily retrieve those notes
- Identifies the patient's healthcare agents (person given authority to make medical decisions for the patient) and other surrogates
- Assists with referrals to advance care planning facilitators



National Comparison: www.dartmouthatlas.org/data_tools.shtm

When compared with other hospitals in the country, Gundersen Lutheran ranks near the bottom when it comes to Medicare costs associated with chronic disease in a patient's last two years of life.

Hospital-based Palliative Care

Gundersen Lutheran developed its innovative hospital-based palliative care program three years ago. The program provides inpatient care for patients with end-stage disease suffering an acute medical crisis. Palliative care is an extension of hospice-style care that helps patients with advanced diseases and their families through the physical, psychosocial and spiritual aspects of aging and dying.

Gundersen Lutheran's innovative hospital-based palliative care program has shown to:

- Significantly reduce hospital costs: In the first 15 months of the program, hospital costs were reduced by approximately $3,500 per patient in billed costs
- Increase admissions to hospice care: 32% increase since 2007
- Reduce hospital readmission rates: 6% versus 18% in a control population
- Result in higher ratings of satisfaction with care from families of patients who die in the hospital

Patients can also receive palliative care services in the outpatient setting, resulting in an increased continuity of care.

Next step:
Model for Late Life Care

Gundersen Lutheran Health System is incorporating all of the elements of its advance directives program to create a national model for more efficient, high-quality care for patients nearing the end of life. Rather than focusing on disease management, dependent on medical specialists and a high use of medical services, this system is designed to efficiently help patients live as well as possible in their last two years of life.

This model of care is specifically designed for patients who have serious, eventually fatal, chronic conditions. It features an interdisciplinary care team dedicated to providing high quality, seamless medical care, individualized for each patient and family across all settings of care, from home to hospital. We call this new end-of-life model "Late Life Primary Care" and we expect it to reduce healthcare costs by 25 to 50 percent nationally.

Gundersen Lutheran Health System

Headquartered in La Crosse, Wis. Gundersen Lutheran Health System provides quality health services to patients at its hospital and clinics throughout western Wisconsin, southeastern Minnesota and northeastern Iowa. Gundersen Lutheran is a major tertiary teaching hospital, providing a broad range of emergency, specialty and primary care services to its patients.

As one of the nation's largest multi-specialty group medical practices, Gundersen Lutheran is comprised of nearly 700 medical, dental and associate staff, and supported by a staff of more than 6,000. The Health System has been named among the top 100 in the nation 13 times in the last 11 years.

Jeff Thompson, MD
Chief Executive Officer
Gundersen Lutheran Health System
Phone: (608) 775-2219
JEThomps@gundluth.org
1900 South Avenue
La Crosse, Wisconsin 54601

Joan Curran, MBA
Chief Government Relations and
External Affairs Officer
Gundersen Lutheran Health System
Phone: (608) 775-4347
JLCurran@gundluth.org
1900 South Avenue
La Crosse, Wisconsin 54601

External Affairs Department 1900 South Avenue, GB2-004 La Crosse, WI 54601
Phone: 800-362-9567 or 608-782-7300 Fax: 608-775-6225

Senator WHITEHOUSE [presiding]. Thank you, Ms. Curran. Now before we go to Mr. O'Connor, I want to acknowledge the arrival of Chairman Rockefeller, my Chairman on the Intelligence Committee, who is probably the leading champion in the Senate on these issues, particularly as it relates to the Federal healthcare system. So we are extremely honored, Chairman, that you are here. I invite you to say a few words, if you would like.

Senator ROCKEFELLER. I'm rendered speechless. I will honor this Committee by saying nothing—ask questions.

Senator WHITEHOUSE. Very good. Mr. O'Connor?

STATEMENT OF JOSEPH O'CONNOR, CHAIR, COMMISSION ON LAW AND AGING, AMERICAN BAR ASSOCIATION, BLOOMINGTON, IN

Mr. O'CONNOR. Thank you, Mr. Chairman and members of the Committee. I am here as Chair of the Commission on Law and Aging of the American Bar Association which has tracked the changing legal landscape of state health decisions legislation for more than 20 years. We have provided details of these changes in our written testimony and ask that the written testimony be admitted into the record.

Since 1976 when California adopted the first so-called living will statute, the legal framework of health decisions law has evolved incrementally. States initially placed strong emphasis on standardized legal formalities and procedures. These were requirements and limitations intended to serve as protections against abuse and error.

I will call this approach the legal transactional approach, which focused on the formalities of creating and implementing specific legal instruments to direct or delegate health care decisions including standardized statutory forms, required disclosures or warnings, prescribed phrases or words or even font size and prescribed witnessing or notarization. However research over the last 30 years has found that the legal transactional approach often served to impede rather than promote effective advance care planning. In recognition of these shortcomings, state policies gradually moved toward a more flexible process of communication. This communications paradigm involves efforts to discern the individual's changing priorities, values and goals of care and to meaningfully engage a proxy and others who will participate in the healthcare decision-making process.

The 1993 Uniform Healthcare Decisions Act represented the first concrete milestone in this redirection by offering a model of simplicity that prompted many states to combine disparate, statutory and regulatory provisions into simpler, comprehensive acts. Complementing this trend in the law is a growing awareness of policy that no matter how good the communication may be between patient, family and physician, healthcare is provided in a regimented, confusing and fast moving system in which patient wishes can easily be overlooked. How can we make sure that the goals and preferences of the patients are actually translated into the language and processes of the healthcare system?

An emerging strategy that began in Oregon has had a positive impact in bridging this crucial gap. It's called Physician's Orders for Life Sustaining Treatment or POLST, as well as by other names in different states. To date, eight states have authorized the use of versions of the POLST Paradigm, statewide and parts of several other states are implementing it on a local basis.

The primary Congressional foray into this subject is the Patient Self Determination Act of 1990 which at its heart is an information and education mandate. It didn't create or change any substantive right to healthcare decisionmaking. But it did require that patients be asked if they had an advance directive and be given information about them.

Congress took a more proactive approach in 1996 for military personnel by expressly exempting directives of military personnel from state law requirements. Given the unique need of military personnel this exception can't really be viewed as trend toward greater Federal control over advance directive law. But it does raise the question about what actions might be effective in encouraging a policy and practice shift supportive of the communications model of advanced care planning.

Our written testimony enumerates several possible strategies with some of their pros and cons which we offer as ideas for consideration, not as policy prescriptions. I will highlight three of these.

Overcoming the variability of state law. Congress could expand the military "advanced directive" approach and in effect, create a Federal "advanced directive," at least for Medicare and Medicaid patients. But of course, that strategy raises obvious state rights issues as well as the danger that a standardized Federal form would, like state forms, put more emphasis on formality rather than on reflection and communication.

The second effort might be to affirm the principle of self determination. This principle is central to both common law and constitutional law. Yet it sometimes is limited by the formalities of state "advanced directive" laws.

Idaho's statute provides an instructive affirmation of the principle. Their advanced statute simply states, "Any authentic expression of a person's wishes with respect to healthcare should be honored." This does not create any new writer obligation. It merely cites in simple terms a fundamental principle and focuses the inquiry on accurately determining the person's wishes and goals. It also clarifies the roles of statutory advanced directives as one means of communication, but not the only.

The third would be to encourage the POLST Paradigm. Congress could require that providers have a process to convert treatment and goals and preferences of persons with life limiting illness into a highly visible, medical orders and to ensure that this information is transferable across all care settings. This, of course, is what POLST does.

With that I will close. I thank you for giving me this opportunity on behalf of the ABA to submit a perspective on this important subject. Of course, I would be happy with the panel members to answer any questions we can.

[The prepared statement of Mr. O'Connor follows:]

AMERICAN B[illegible]
GOVERNMENTAL AFFAIRS OFFICE • 740 FIFTEENTH STREET, NW • [illegible] DC 20005 [illegible]

STATEMENT

of

JOSEPH D. O'CONNOR

Chair

AMERICAN BAR ASSOCIATION COMMISSION ON LAW AND AGING

on behalf of the

AMERICAN BAR ASSOCIATION

presented to the

SPECIAL COMMITTEE ON AGING

of the

UNITED STATES SENATE

on

HOW TO RESPECT AMERICANS' CHOICES AT THE END OF LIFE

September 24, 2008

Mr. Chairman and Members of the Committee:

I appreciate this opportunity to present the perspective of the American Bar Association on the development of state and federal health care advance directive policy. I currently chair the ABA's Commission on Law and Aging, which has followed and provided technical assistance and education on health care advance planning for over 20 years. I would like to describe how advance directives for health care decisionmaking have evolved in the last three decades, highlighting some of the implications that has for present and future policy options at the state and federal level.

Incremental State Evolution

The first advance directive – popularized by the term *living will* – was proposed by the Luis Kutner, a human-rights lawyer from Chicago. He proposed it in a 1969 *Indiana Law Journal* article as an instrument by which an individual could refuse treatment prior to losing capacity, even if such treatment would prolong life.

Borrowing this concept, California adopted the first living will statute in 1976 (although it used the term "directive to physicians" rather than the popular "living will"). The paradigm offered individuals a standardized tool to express their wishes about life-sustaining treatment – usually to withhold or withdraw it – in the event of a terminal condition or permanent unconsciousness; and to physicians it offered statutory immunity if they complied with the patient's wishes in good faith. This legal model for directing decisions focused on conventional legal formalities or procedural protections was intended to protect vulnerable populations from harm, specifically the premature termination of life due to lack of understanding, or diminished capacity of, or undue influence upon, the signor of the living will.

In the ten years after 1976, a *first wave* of advance directive legislation rolled through the states, so that by the end of 1986, 41 states had adopted living will laws. But it was not long before the shortcomings of living wills became apparent to policymakers, especially with respect to the narrow range of decisions it applied to. Policymakers turned to validating and reshaping the use of durable powers of attorney to apply to health care.

The conventional view of powers of attorney is that they can be used for any purpose not contrary to law or public policy of a given state. Their use as a health care decision-making tool had an obvious advantage over the living will, but many also expressed concerns that durable power statutes, focused on property matters, lack rigorous procedural protections that may be needed to deter potential misuse of these instruments in the context of serious decisions about life-support.

To address these concerns while encouraging their use, states began crafting special durable power of attorney for health care statutes or, alternatively, adding proxy provisions to their living will statute. This *second wave* of advance directive legislation took place roughly from the mid-1980s to the mid-1990s, with California again leading the pack with its 1983 law. By the end of 1988, only twelve states had such statutes, but by the end of 1997, the District of Columbia and every state had enacted some version of a health care power of attorney statute.

A *third wave* of legislation began in the early 1990s, triggered by a growing awareness of unwanted cardio-pulmonary resuscitation attempts of terminally ill patients living at home or in nursing homes or hospice, occurring when the expected medical crisis arises and someone on the scene calls 911. Absent an out-of-hospital do-not-resuscitate protocol, emergency medical services personnel are obligated to do everything possible to resuscitate a patient whose heart or breathing has stopped unless the patient himself or herself refuses help. An advance directive does not normally trump that obligation. To address these unwanted medical encounters, states began enacting out-of-hospital DNR legislation or regulations. These protocols, also called Comfort Care Orders or CPR directives usually require the signing of a DNR order by both physician and patient (or patient surrogate) and the use of a specially designed identifier, such as a bracelet, to be kept on or near the patient. By the end of 1999, 42 states had statewide protocols in place, most frequently created by legislation.

A *fourth wave* of legislation was not so much a wave as a slowly rising tide, going as far back as the 1960's and continuing to the present. Unlike the advance directive waves, this trend addressed the other side of the decision-making coin – how decisions are to be made *in the absence of an advance directive*. An awareness that the great majority of Americans were not utilizing advance directives fueled interest in this subject. As is still the case today, most decisions relating to end-of-life care for persons lacking decisional capacity are made without the guidance or authority of a health care advance directive. State law frequently failed to identify who, in the absence of an appointed agent or guardian, was authorized to make decisions in these instances.

Default surrogate consent or family consent laws provide an answer to that question. These exist is some 40 states and the District of Columbia, although they vary significantly in scope of decision-making and limitations on surrogate authority. All create a list of permissible surrogates, usually in a priority order starting with spouse and covering next-of-kin. Twenty-one states include "close friend" or its equivalent in the list of permissible surrogates, usually at or near the end of the order of priority.

A significant *fifth wave* of state legislation began as a merging of the separate health care decisions acts states had already enacted. This was driven, in part, by the public's lack of understanding these legal tools and their lack of use. Most estimates of completion rates in the early 1990's hovered around 20 percent or less. And, a substantial lack of awareness and misunderstanding of advance directives persisted.

New Jersey enacted the first combined statute in 1991, merging the living will (called an "instruction directive") and the durable power of attorney for health care (called "a proxy directive") into a single "advance directive for health care," N.J. Stat. Ann. §26:2H-53 to -81 (West 2007). By the beginning of 2000, some 16 states had comprehensive or combined advance directive statutes, which at a minimum, combined living wills and proxies in the same law. Today, that number has risen to 26 states. During the 1990s, interest also grew in establishing special advance directives for mental health decisions, but because these focus on a distinctive set of issues not directly related to end-of-life decision-making, they are not covered in this review.[1]

The primary model for a flexible combined-advance directive and default surrogate law has been the *Uniform Health-Care Decisions Act.* The *Uniform Act* was promulgated as a national model by the Uniform Law Commissioners in 1993, and recognized by the American Bar Association in 1994. The Act establishes very simple rules for recognizing almost any kind of written or oral statement as an advance directive. Even unwitnessed documents are valid under the Uniform Act. However, states that have adopted the *Uniform Act* have almost always added more to the Act's baseline requirements. Indeed, all states that have adopted it have added

---

[1] For more information on psychiatric advance directives, see the web page of the National Resource Center on Psychiatric Advance Directives at < http://www.nrc-pad.org/index.php>.

at least a witnessing requirement. The Act provides a comprehensive, sample form with options for instructions, appointment of an agent, organ donation, an option to name a primary physician, and the recognition of default surrogates in the absence of an advance directive.

Our Commission's provides summary charts of current health decisions legislation and annual legislative updates. These can be found at: http://www.abanet.org/aging/legislativeupdates/home.shtml.

The Federal Role

The federal legislative role in the above evolution of advance directives has been fairly minimal. The primary congressional foray into this subject is the Patient Self-Determination Act, enacted as part of the Omnibus Budget Reconciliation Act of 1990.[2] The Act was a fairly modest amendment to federal Medicare and Medicaid law, spearheaded by Missouri's then Senator John Danforth. It was hoped that the Act would encourage adults to think about and plan for health care decisions. It also legislatively affirmed the use of the term "advance directive". At its heart, it is an information and education mandate. It did not create or change any substantive right to health care decision-making. Rather, it requires all Medicare and Medicaid provider organizations (specifically, hospitals, skilled nursing facilities, home health agencies, hospices, and prepaid health care organizations) to do five things:

(1) provide written information to patients concerning their right under state law to make decisions about their medical care and the right to formulate advance directives;

(2) maintain written policies and procedures regarding advance directives and make them available;

(3) document whether or not the individual has executed an advance directive;

(4) comply with the requirements of state law respecting advance directives; and

(5) provide staff and community education on advance directives.

The Act specifically prohibits any form of discrimination based on advance directives. To promote the dissemination of accurate public information, the Act further mandated states to develop written descriptions of state law for distribution by providers or organizations.

---

[2] The Patient Self-Determination Act was enacted as part of the Omnibus Budget Reconciliation Act of 1990, signed by the President on November 5, 1990. Omnibus Budget Reconciliation Act (OBRA) of 1990, Pub. L. No. 101-508, §§4206 and 4751 (Medicare and Medicaid, respectively), codified in part at 42 U.S.C. §§1395cc(a)(1)(Q), 1395cc(f), 1395mm(c)(8), 1396a(a)(57), 1396a(a)58, 1396a(w).

Finally, the Act required the U.S. Department of Health and Human Services (DHHS) to undertake a public education campaign.

Because health-care decision making has traditionally been considered a province of state law, federal law generally defers to state substantive law in this area, including the selection and authority of appointed agents and default surrogates. However, with respect to one group of citizens, military personnel, Congress in 1996 enacted a federal advance directive that explicitly pre-empts state law:

> 10 U.S.C.A. § 1044c. **Advance medical directives of members and dependents: requirement for recognition by States**
>
> (a) Instruments to be given legal effect without regard to state law.--An advance medical directive executed by a person eligible for legal assistance--
>
> (1) is exempt from any requirement of form, substance, formality, or recording that is provided for advance medical directives under the laws of a State; and
>
> (2) shall be given the same legal effect as an advance medical directive prepared and executed in accordance with the laws of the State concerned.
>
> (b) Advance medical directives.--For purposes of this section, an advance medical directive is any written declaration that--
>
> (1) sets forth directions regarding the provision, withdrawal, or withholding of life-prolonging procedures, including hydration and sustenance, for the declarant whenever the declarant has a terminal physical condition or is in a persistent vegetative state; or
>
> (2) authorizes another person to make health care decisions for the declarant, under circumstances stated in the declaration, whenever the declarant is incapable of making informed health care decisions.

More recently, Congress added end-of-life planning to the "Welcome to Medicare" exam for Medicare beneficiaries. More about this is included under the options for action below.

The Paradigm Shift in State Law

Historically, the state legal landscape of advance directive law has emphasized standardized legal formalities with procedural requirements or limitations intended to serve as protections against abuse or error. For shorthand, this may be referred to as a *legal transactional approach* to advance directive policy. However, state policy has been in a very gradual state of flux and moving toward an approach that more strongly acknowledges an ongoing and flexible process of communication-- which may be referred to as a *communications approach.*

The *legal transactional framework* focuses on the formal steps of creating and implementing specific legal tools to direct or delegate health care decisions in advance of decisional incapacity. In this light, the creation of an advance directive is treated much like conventional conveyances of interests in property or contracts that establish important rights and obligations. The validity of the transaction focuses on required legal formalities and standardization of the process.

Because states anticipated that these legal tools typically would be commonly signed and used without the advice of legal counsel, detailed standardized formalities were relied upon to ensure the voluntary, knowing, and competent execution of the transaction— the same elements central to medical informed consent. However, completing an advance directive is clearly not the same as giving medical informed consent, because advance directives address simple future hypothetical situations, not here-and-now, complicated medical decisions. Standardization was also driven by the assumption that it would enhance the recognition of and compliance with advance directives by health care providers.

Conventional legal formalities for execution of advance directives have included requirements such as:

- Standardized statutory forms.
- Required disclosures or warnings for anyone completing an advance directive.
- Prescribed phrases or words or even font size for authorizing certain wishes.
- Required witnessing or notarization and restrictions on who may be a witness.
- Limitations on who may serve as agent or proxy.

The legal transactional approach also utilizes an array of mandatory procedures or other limitations intended as protective safeguards. A recent review of the limitations on surrogate decision-making conducted by our Commission identified the following examples occurring in varying frequency:

- Living will statutes typically impose medical diagnosis prerequisites before taking action (usually a diagnosis of terminal condition or permanent unconsciousness); but a dozen states also require a diagnostic precondition before an appointed agent may make decisions about life-sustaining procedures.
- A majority of states impose limitations on implementing advance directives if the patient is pregnant.

- Twelve states include limitations that prohibit a surrogate from consenting to controversial medical interventions such as sterilization or abortion or psycho-surgery.
- Thirty-three states have special limitations on consent by agents, default surrogates, or guardians to forgo artificial nutrition or hydration. These range from an absolute bar on default surrogates to required diagnostic preconditions.

Despite its legitimate goals, the legal transactional approach to advance care planning may have served to impede rather than promote effective advance care planning. An ample body of research, summarized by Fagerlin and Schneider and others,[3] reveals that conventional advance directives, especially living wills, have had relatively little impact on end-of-life decision making. Tersely summarized, some of the significant reasons for the lack of impact include the following:

(1) Too few people make use of the legal tools;

(2) When they do, they do not understand the forms they complete nor the future decisions that might have to be made;

(3) The forms themselves don't provide much guidance;

(4) Patent's goals and preferences for care may change;

(5) When principals name an agent or proxy, the agent seldom understands the principal's wishes;

(6) Even if they have done all the above, health care providers usually don't know about the directive;

(7) And even if providers know one exists, it does not affect patient care.

The Institute of Medicine in its 1997 report on improving care at the end of life likewise

---

[3] Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 The Hastings Center Report 30-42 (March-April 2004). A sampling of related literature includes: Bernard Lo & Robert Steinbrook, *Resuscitating Advance Directives*, 164 Arch. Intern. Med. 1501-06 (July 26, 2004); Peter H. Ditto, *et. al*, *Advance Directives as Acts of Communication*, 161 Arch. Intern. Med. 421-430 (2001); Joan M. Teno, Marguerite Stevens, Stephanie Spernak & Joanne Lynn, *Role of Written Advance Directives in Decision Making: Insights from Qualitative and Quantitative Data*, 13(7) J. Gen. Intern. Med. 439-447 (1998); E.J. Larson and T.A. Eaton, *The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act*, 32 Wake Forest L. Rev. at 278 (1997); J. Teno *et al*, *Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention*, 45 J. of the American Geriatrics Society 500-507 (1997); David Orentlicher, *The Illusion of Patient Choice in End-of-Life Decisions*, 267 JAMA 2101-2104 (1992); Diane E. Hoffmann, Sheryl I. Zimmerman & Catherine J. Tompkins, *The Dangers of Directives or the False Security of Forms*, 24 J. of Law, Medicine & Ethics 5 (1996); Rebecca Dresser, *Confronting the 'Near Irrelevance' of Advance Directives*, 5 J. Clin. Ethics 55-56 (Spring 1994).

questioned the wisdom of conventional advance directives:

> The committee, while recognizing the value of advance directives, questions the urgency of intensive efforts to universalize their use. In this area of decision making at the end of life, the law's favorite product—the legally binding document – may sometimes stand in the way of, rather than ease, the process, especially if these documents are naively viewed as ultimate solutions to the difficulties of decision making. Rather, the documents known as advance directives should be seen as a set of tools useful in the ongoing process of advance care planning.[4]

In response to the experienced shortcomings of the transactional approach, an alternative paradigm has emerged – a *communications approach*. This paradigm derives from the concept of *advance care planning* described by the Institute of Medicine as follows:

> [A]dvance care planning is a broader, less legally focused concept than that of advance directives. It encompasses not only preparation of legal documents but also discussions with family members and physicians about what the future may hold for people with serious illnesses, how patients and families want their beliefs and preferences to guide decisions…, and what steps could alleviate concerns related to finances, family matters, spiritual questions, and other issues that trouble seriously ill or dying patients and their families.[5]

Advance care planning involves an iterative process over time to discern the individual's priorities, values, and goals of care and to engage a proxy and others who will participate in the health-care decision making process at any time in the future when the individual is no longer able. This revised approach to health care advance directive policy is by no means new, but only fairly recently has its implications for public policy, as reflected in advance directive laws, been taken seriously. A review of current trends in advance directive laws reveals incremental but real steps toward simplification of state law, especially with respect to mandatory forms or language. The 1993 Uniform Health-Care Decisions Act represented the first major milestone in this redirection by offering a model of simplicity that prompted many states to combine disparate pieces of health care decision-making provisions into simpler, comprehensive acts.

One instructive measure of simplification is the extent to which state law has become uncomplicated enough to enable a single advance directive form to meet the statutory requirements of all 50 states and the District of Columbia. The *Five Wishes* advance directive provides one such measure. In the last ten years, the *Five Wishes* advance directive, created by

---

[4] Institute of Medicine, Committee on Care at the End of Life, *Approaching Death: Improving Care at the End of Life* 203 (Marilyn J. Field & Christine K. Cassel, eds., Natl. Acad. Press 1997).
[5] *Id.*, at 198-199.

the organization Aging with Dignity, Inc., has been the only form affirmatively marketed nationally.[6] Five Wishes aspires to be a personal, easy-to-use, and non-legalistic instrument. When *Five Wishes* was released in 1978, it claimed to meet the statutory requirements of 33 states and the District of Columbia.[7] The most prominent barriers to the statutory compliance of *Five Wishes* were statutory requirements for substantial compliance with statutory forms along with prescribed phraseology or requirements for including prescribed notices or warnings. By 2007, the number of state laws friendly to *Five Wishes* had grown to 40. The increase was made possible by the trend toward simplification by state legislators.

Another indicator of simplification is a trend toward the statutory recognition of oral advance directives documented in the patient's record. Prior to the 1993 Uniform Health-Care Decisions Act which permitted oral directives, no state recognized oral advance directives. Today, 15 states recognize some form of oral directive. Most of these states follow the approach of the *Uniform Act* which recognizes an oral "instruction" documented in the record as valid and the appointment of an orally designated "surrogate" where the appointment is personally communicated to the supervising health care provider.

Apart from legislation, one aspect of advance directive practice in the field deserves notice. The tools available to the public under the legal transactional paradigm have primarily been statutory forms and the instructions for completing them and related fact sheets. Beginning in the late 1990s, self-help tools began to appear intended to help the user to understand the process of planning, the values and goals to be considered, and how to discuss these matters with family, friends, proxy, and health care providers. These are essentially workbooks for advance care planning. The written directive is still an intended outcome, but the primary emphasis is placed on the process, not the form.

Robert Pearlman and others at the Veterans Administration Medical Center in Seattle produced one of the first of these in 1998, entitled *Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will.* A small sampling of others that have appeared include:

- *Caring Conversations Workbook*, published by the Center for Practical Bioethics (1999).

---

[6] Aging With Dignity, Inc., is a non-profit group that assists families with end-of-life issues. *See* http://www.agingwithdignity.org.

[7] Charles P. Sabatino, *National Advance Directives: One Attempt to Scale the Barriers*, 1 NAELA Journal 131-164 (Spring 2005).

- Finding Your Way: A Guide for End-of-Life Medical Decisions, by Sacramento Healthcare Decisions (1998).
- The Critical Conditions Planning Guide, by Georgia Health Decisions (1998).
- *The Lawyer's Tool Kit for Health Care Advance Planning,* and the *The Consumer's Tool Kit for Health Care Advance Planning* by the ABA Commission on Law and Aging (2000).

The *Lawyer's Toolkit* is significant in its targeting of the legal profession which assists a sizeable proportion of individuals to complete advance directives. The *Toolkit* does not provide guidance in drafting, but instead gives lawyers tools they can provide to clients to help them understand the planning process, self-reflect, and discuss the subject with family, physician, and others. Use of resources such as these by no means marks the end of the transactional legal model, but it is indicative of the growing awareness of the communication process as the ultimate goal of advance directive public policy.

An Emerging Next Step – the POLST Paradigm

As law and practice move toward a less standardized, more flexible, communications approach, questions remain as to whether more flexibility in communication will have any greater impact on actual treatment decisions than do standardized advance directive forms. An emerging strategy that began in Oregon has an impact in bridging this gap between patient goals and preferences – expressed directly, through an advance directive, or by a proxy – and the actual plan of care as reflected by physician orders.

Oregon and a growing number of other states have concluded that patient wishes, no matter how communicated, must be systematically factored into or translated into the medical decision-making engine. In the early 1990s, Oregon experimented with a protocol for seriously chronically ill patients, called *Physicians Orders for Life-Sustaining Treatment*, or POLST. There are several ways to describe the POLST process, but relevant to this review are three key tasks it aims to accomplish.

- One, use of POLST prompts a discussion between health care providers and patients with life-limiting medical conditions about high-probability treatment scenarios. The objective is to discern the wishes of the patient in light of his or her current condition and the available care options as explained by the treating health care provider.

- Two, the patient's wishes are incorporated into doctor's orders that are recorded on a unique, visible (bright pink in Oregon) form. The form covers several key decisions that are common for seriously chronically ill patients, for example: cardiopulmonary resuscitation; the level of aggressive care desired in the event of emergency (full treatment; limited; or comfort only/do not hospitalize); use of antibiotics; and the use of artificial nutrition and hydration.
- Three, providers must ensure that the POLST form travels with the patient whenever transfers from one setting to another are made, thus, promoting continuity of care in decision making. At the same time, the orders are reviewed periodically and as needed.

POLST is not an advance directive in the conventional sense but it is an advance care planning tool that reflects the patient's here-and-now goals for medical decisions that could confront the patient in the immediate future. It builds upon one's advance directive but can also benefit those patients -- still a majority -- who refrain from using advance directives. Research on the Oregon experience with POLST has shown positive outcomes.

The precursor of the POLST paradigm is the out-of-hospital do-not-resuscitate order, now common in virtually every state. POLST is a similar process, except that it is not limited to the single decision of resuscitation, and it does not presumptively call for withholding medical interventions. It permits a full range of intervention options.

Since Oregon's development of the POLST form, Washington, West Virginia, Utah, North Carolina, New York, Maryland, and most recently, California have authorized the use of various versions of the POLST paradigm statewide, often using different nomenclature for the paradigm. Parts of several other states have implemented similar protocols locally, and other states are considering following suit. Detailed information on POLST can be found at http://www.polst.org.

Options for Federal Action

If Congress wished to encourage the policy and practice shift towards a communications model of advance care planning, several options exist. Eight are enumerated here in no particular order of priority. These are offered as thought experiments, not as policy prescriptions

1. Overcoming the Balkanization of State Law.

Congress could give consideration to the appropriateness of addressing the problems posed by confusing interstate differences in the law by creating a federal advance directive that would be deemed valid in all states. The strategy would likely face political resistance on states' rights grounds. In addition, the effect of a federally sanctioned advance directive form does not avoid the very same problems states have encountered in creating their own statutory forms. One size does not necessarily fit all, and an unintended consequence could be to further legalize and formalize a task that is very personal and private at heart.

2. Affirming the Principle of Self Determination.

One of the unintended consequences of statutory advance directive forms, even those that are expressly optional, is that practice often embraces the statutory form as the only safe alternative, thus exacerbating the one-size-fits-all shortcoming of advance directives. That perception can exist even though both the common law and constitutional law principles clearly require health care providers to respect the known wishes of their patients, no matter how communicated. Some suggest that a simple strategy to promote a communications model of advance planning might be to affirm this principle in federal law. Idaho provides an example of this strategy. The concluding sentence in the statement-of-purpose section of Idaho law states simply: "Any authentic expression of a person's wishes with respect to health care should be honored."

The statement does not create any new rights or obligations in Idaho; it merely recites in simple terms a fundamental principle of the common law and constitutional law. Applied to any clinical setting, it focuses the inquiry on accurately determining the person's wishes and goals rather than on whether the individual accurately complied with legal formalities. The principle often gets buried under the legalistic formalities of state laws. By expressly communicating and applying this principle to those providers who participate in Medicare and Medicaid and other federal health care programs, the Congress could clarify the proper role of statutory advance directives as one means of communication but not the only. Affirmation of the principle could also encourage the development and use of a variety of nationally distributed advance directive tools without creating a federal model form.

3. Affirming Portability.

While portability of advance directives across state borders has not been shown to be a major problem, it does persist in perception because of the variability of state laws. This is a concern that has been targeted in several proposed amendments to the Patient Self-Determination Act over the last few years, although none of these proposals has been enacted.

4. Encouraging the POLST Paradigm

Some have suggested that Congress could encourage all states to adopt protocols with goals similar to that of Physicians Orders for Life-Sustaining Treatment. This could be done by adding to proposed PSDA language a requirement that states, or providers under Medicare and Medicaid, have a process to convert treatment goals and preferences of persons with life-limiting illness into medical orders (e.g. the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Initiative) to ensure that the information is transferable and applicable across all care settings.

5. Physician Reimbursement.

Payment for physician advance planning consultations has been a recurring recommendation as a strategy for enhancing advance planning. However, the potential price tag for physician reimbursement of a new service has posed a fatal barrier to such legislation in the past. Current bills before Congress scaled back the idea to one end-of-life planning consultation as part of the initial preventive physical examination to Medicare (sometimes called the "welcome to Medicare exam"). This past July, Congress enacted the Medicare Improvements for Patients and Providers Act of 2008", PL 110-275 (HR 6331), which adds "end-of-life planning" to the initial preventive physical exam that Medicare beneficiaries are entitled to when they enroll in Medicare. "End-of-life planning" is defined as:

> verbal or written information regarding--
> (A) an individual's ability to prepare an advance directive in the case that an injury or illness causes the individual to be unable to make health care decisions; and
> (B) whether or not the physician is willing to follow the individual's wishes as expressed in an advance directive.[8]

---

[8] Medicare Improvements for Patients and Providers Act of 2008", PL 110-275 (HR 6331). Section 101 of that Act amends 42 U.S.C.A. §1395x(ww).

The language acknowledges the physician's central role in prompting advance planning, although it is a minimal requirement that on its face can be complied with by handing patients another piece of paper with more information.

6. Public Education and Information

Several proposals have been made in the last few Congresses to require that the Department of Health and Human Services conduct various kinds of public education campaigns to raise awareness of the importance of planning for care near the end of life, or to create a national information clearinghouse where consumers could receive state-specific information and consumer-friendly documents and publications. Both the clearinghouse and public education campaign represent helpful and familiar strategies for encouraging behavior change, even though most education intervention efforts examined in the literature have not been shown to have much effect on advance planning behavior. Nevertheless, federal resources for such efforts would be welcomed by many. A more ambitious role for the federal government would be to fund research and demonstration efforts for a more intensive social marketing campaign to engage the public in the communication process of advance planning.

7. Supporting Advance Directive Registries.

Not a great deal is known about the effectiveness of registry strategies, although the states are showing strong interest in developing advance directive registries as a way to enhance provider access to advance directives. It is unclear what effect the transition to electronic records, strongly supported by the federal government, will have on the need for separate registries. These questions invite a role for the federal government either to support research financially on these strategies or to support them directly through reimbursement of state costs for creating registries. Alternatively, the government could focus on the goal of a national registry, either through financial incentives or the creation of a federal registry. All these options pose administrative challenges and privacy issues that would have to be carefully addressed.

8. Cultural Diversity

Finally, an underlying social reality that is not touched upon by this review is how and whether advance planning as currently framed in public policy is either effective or appropriate across the wide array of cultures and special populations represented in our society. The values of equal protection and equal opportunity would argue for a strong federal role in supporting research and demonstration efforts to ensure culturally inclusive public policy with respect to health care decision-making. The legislative trends towards simplification of advance planning, including the use of oral directives, appear to fit well with the goal of greater cultural sensitivity.

In conclusion, if Congress chooses to consider taking action in this area, it is important to think about options in the context of the central trends in state advance planning policy – i.e., the movement of the states away from a legal transactional mode of advance planning toward a communications model. While, much of the evaluative scholarly literature is supportive of that trend, many questions persist. In some respects, the work of this transition has been to get the law out of the way of good planning – i.e., making it simpler, less legalistic in requirements, and more adaptable to modes of communicating and decisionmaking natural to a wide variety of individuals and cultures. At the same time, concerns about potential abuse cannot be blithely discarded. While no significant patterns of abuse have been identified in the research literature, the fact that these decisions do indeed involve life and death consequences, the protection of vulnerable persons will remain a challenge.

Thank you for giving me this opportunity to present the American Bar Association's perspective to you on this important subject.

Senator WHITEHOUSE. Thank you, Mr. O'Connor. Dr. Meier, we're now delighted to turn to you.

STATEMENT OF DR. DIANE E. MEIER, GAISMAN PROFESSOR OF MEDICAL ETHICS, DEPARTMENT OF GERIATRICS, MOUNT SINAI SCHOOL OF MEDICINE, NEW YORK, NY

Dr. MEIER. Senator Whitehouse, Chairman Kohl and other distinguished Committee members, thank you for this opportunity to speak with the Senate Special Committee on Aging. I am a Geriatrician and a Palliative Care physician at the Mount Sinai School of Medicine in New York City. What I'm going to talk about today is not advanced care planning per say, but about palliative care which is strongly related to it and will be a somewhat different perspective than what you'll be hearing from my colleagues on the panel.

Palliate care is medical care focused on relief of suffering, and support for best possible quality of life for people with serious illness and their families. It is delivered at the same time as all other appropriate medical care including curative or life prolonging, care should that be appropriate for the patient.

In addition to my work at Mount Sinai I lead a national initiative called the Center to Advance Palliative Care whose mission is to improve access to the quality of palliative care in American hospitals. I was drawn to this work because of my distress over many decades working in a large academic teaching hospital about how our sickest and most vulnerable fellow citizens are treated in U.S. hospitals. I'm going to tell you a story about one of my patients which I think exemplifies the urgent need for palliative care in hospitals. I hope that will put a human face on the data that I will be presenting subsequently.

Mrs. J was an 85 year old woman with multiple problems including dementia, coronary disease, kidney failure, who was admitted to the ICU with a bloodstream infection. Her hospital course was complicated by the development of gangrene in her left foot and many deep pressure ulcers on her back resulting from prolonged, intensive care unit bed rest. She underwent five surgical debridements of her wounds under general anesthesia. When they were asked by her primary doctor, her family consistently said they wanted everything done.

On day 63 of her hospital stay a palliative care consult was initiated to help clarify the goals of this hospitalization and to treat Mrs. J's evident pain and discomfort. She was persistently moaning in pain and would scream and lash out and resist care when the nurses tried to change her surgical dressings.

The Palliative Care team, me, a nurse, a social worker and a couple of medical students, met with her son who was her health care proxy and her two grandchildren. During what turned into a 90 minute discussion, we clarified confusion about her diagnosis and prognosis. We asked the son a different question. We asked him what he was hoping we could accomplish for his mother. What he said was, "she's in so much pain. Why can't they do anything about it? They said the pain medicines would make her more confused, but she gets more confused every day that I come to see her. When I visit all she does is moan and turn her face away from me."

Possible sources of discomfort and pain were identified. A treatment plan including morphine for her pain and extra doses of morphine 30 minutes before dressing changes was initiated. We started Tylenol for her fevers. We stopped the antibiotics which she'd been on for two months with absolutely no benefit to her fevers or her wounds.

She got pain relief and had a marked improvement in mood, interaction and function. She began to tolerate her dressing changes without resistance, participated in physical therapy, actually was able to get out of bed and into a chair and enjoyed visits with her family. She was discharged from the hospital several days later back to the nursing home that she had lived in before she was admitted to the hospital but this time with a referral for hospice care on return to the nursing home.

The Hospice team followed the care plan that was developed in the hospital and continued provision of expert pain management and expert wound care. The patient slowly recovered actually near to her previous state of health and awareness and interaction. The family expressed tremendous satisfaction with the resolution of her stay and continued to visit her daily in the nursing home where they reported to me that she was interactive and comfortable.

Patients like these are the basis and the motivation for the development of hospital palliative care programs in the U.S. This patient had a health care proxy. This patient had expressed her prior wishes. So it's not that there was a failure of advance care planning.

She was getting the wrong care. She was in the wrong place. She and her family suffered enormously. The cost of her over two month hospitalization, and this was several years ago, exceeded 100,000 dollars. When goals and alternatives were clarified, a process that required skilled and expert communication and discussion with her exhausted and distraught family, the patient was able to go back to her home, be among familiar care givers, her pain was easily controlled her wounds began to heal and she was restored back to herself, a process that required the intervention of the palliative care team to help her get on the right path.

Palliative Care Programs in hospitals are a rapidly diffusing innovation and have been shown in multiple studies to both improve quality and reduce costs for America's sickest and most complex patients. The chronically and seriously ill in the United States constitute only 5 to 10 percent of our patients, but account for well over half of the nation's healthcare costs. Palliative care programs are a solution to this growing quality and cost crisis.

Palliative care is not the same as hospice. Non-hospice palliative care is appropriate at any point in a serious illness from the time of diagnosis. There is no prognostic requirement, and no requirement to give up curative care. Hospice is a form of palliative care provided for people with serious illness who are clearly in the last weeks to months of life-they must have a two MD-certified prognosis of 6 months or less which is very difficult to predict, and must sign a piece of paper giving up their right to insurance coverage for curative care.

Palliative care improves the quality of patient centered care while reducing costs because it begins with the goals and preferences of the patient and the family. As in the case of Mrs. J, palliative care-teams support the development of realistic care plans to meet these goals. How are healthcare costs reduced? Seriously ill patients are actually able to leave the hospital, the most expensive setting of care and get care in settings more appropriate to their needs, often where most of us would like to be, at home.

This is possible because we ensure very sophisticated transition and discharge planning. This patient, Mrs. J could not have gone back to her nursing home without development of a very detailed and expert pain and wound management plan. He was the expertise of the palliative care team that allowed us to safely send her out of the hospital.

Senator WHITEHOUSE. Yes.

Dr. MEIER. Should I stop?

Senator WHITEHOUSE. If you could summarize.

Dr. MEIER. Alright, I'll summarize. Just to say there's enormous state by state variation in access to palliative care, like everything else in the American healthcare system. While there are a lot more palliative care programs than there used to be, if you're a poor person, if you're in a public hospital, a sole community provider hospital or if you happened to be served by a for profit hospital, you are much less likely to have access to palliative care.

The three key barriers to improving access to palliative care are first, that there is no graduate medical education support for palliative care fellowship training because of the cap from the 1997 Balanced Budget Act on graduate medical education. So we cannot pay to train physicians to specialize in palliative medicine.

Second there is no support for junior faculty members trying to be the teachers and the researchers that are needed to promote this kind of care for future generations of doctors and nurses. We are promoting something along the lines of the Geriatric Academic Career Awards, the GACA, but this time for palliative care, Palliative Academic Career Awards.

Third, there has been an appallingly inadequate level of NIH investment in palliative care research. We have absolutely no evidence base to support our work. The major institutes, NCI, NHLBI, NIKKD and others have done little or nothing to support research in palliative care. That imbalance needs to be corrected.

Thank you very much.

[The prepared statement of Dr. Meier follows:]

CENTER TO ADVANCE PALLIATIVE CARE

NATIONAL Palliative Care RESEARCH CENTER

Palliative Care in U.S. Hospitals:

Implications for Access to Quality Healthcare

Diane E. Meier MD

Testimony Prepared for

the United States Senate Special Committee on Aging

September 24, 2008

Professor, Departments of Geriatrics and Medicine
Director, Center to Advance Palliative Care
Director, Hertzberg Palliative Care Institute
Brookdale Department of Geriatrics and Adult Development
Mount Sinai School of Medicine
New York, NY 10029
212 241 1446
212 426 5054 fax
diane.meier@mssm.edu
www.capc.org
www.getpalliativecare.org
www.npcrc.org

Senator Whitehouse, Senator Smith, Chairman Kohl, and other distinguished committee members, thank you for the opportunity to speak before the Senate Special Committee on Aging. I am a geriatrician and palliative care physician at Mount Sinai School of Medicine in New York City where I have an active clinical practice, I conduct research on palliative care and I direct a palliative care consultation and teaching service. Our palliative care program cares for over one thousand patients per year and educates hundreds of medical students, residents, and other health professionals in the principals of pain and symptom management, high quality communication between doctors and patients and families, and helping patients and families negotiate the fragmented and confusing health care system in the U.S. In addition, I lead a national initiative called the *Center to Advance Palliative Care* whose mission is to improve access to quality palliative care across the U.S. I was drawn to this work because of my distress about how our sickest and most vulnerable fellow citizens are treated in the U.S. Too many of the patients I was seeing were suffering from untreated pain, had little to no understanding of what was happening to them nor why, and were spending long periods of time in impersonal and risky hospital settings. The following true story about one of our patients exemplifies the need for palliative care and, I hope, will put a human face on the data I will present in this testimony.

> *Mrs. J was an 85 year old woman with multiple medical problems including dementia, coronary artery disease, kidney failure, and vascular disease who was admitted to the intensive care unit with a bloodstream infection. Her hospital course was complicated by the development of gangrene of her left foot and development of several deep pressure ulcers on her back resulting from prolonged ICU bedrest, and recurrent major infections. She underwent 5 surgical debridements of her wounds under general anesthesia. When they were asked by the primary doctor, her family consistently said that they wanted "everything done".*
>
> *On day 63 of her hospitalization, a palliative care consultation was initiated to help clarify the goals of care and to treat Mrs. J's' evident pain and discomfort. She was persistently moaning in pain and would scream and lash out when the nurses tried to change her surgical dressings. She resisted all efforts to reposition or transfer her or to change her dressings. The palliative care team met with her son (her health care proxy) and her two grandchildren. During a 90 minute discussion, the team reviewed the hospital course*

and clarified any confusion about her diagnosis and prognosis. The team asked the son what he was hoping to accomplish for his mother. He responded "She is in so much pain! Why can't they do anything about it? They said that pain medicines would make her more confused but she gets worse every day that she's here. When I visit all she does is moan and turn away from me." *Possible sources of discomfort and pain were identified. A treatment plan was initiated which included morphine to treat the pain associated with her back and foot wounds with extra doses before dressing changes, discontinuing the antibiotics which were causing resistant infections and had no impact on her wound healing, treating fever with Tylenol, and transferring her to the palliative care unit. The pain relief led to a marked improvement in her mood, interaction, and function- she tolerated her dressing changes without complaint, participated in physical therapy, and recognized and enjoyed the visits of her family. She was discharged from the hospital 2 days later back to the nursing home she had come from, but this time with a referral for hospice care while in the nursing home. The hospice team followed the care plan developed by the hospital palliative care team and continued provision of expert pain management and wound care, and the patient slowly recovered to her previous state of health and awareness. The family expressed tremendous satisfaction with the resolution of her hospitalization and continues to visit her daily in the nursing home where she is reported to be interactive and comfortable.*

Patients like these are the basis and motivation for the development of palliative care programs in the U.S. This patient was getting the wrong care in the wrong place. She and her family suffered enormously, and the cost of her over 2 month hospitalization exceeded one hundred thousand dollars. When goals and alternatives were clarified, a process that required skilled communication and discussion with her distraught family members, an appropriate and effective plan was initiated- the patient was able to go back to her home and be among her familiar caregivers, her pain was easily controlled, and her wounds began to heal- she was restored to herself- a process that required the intervention of a palliative care team to help her get on the right path.

Palliative care programs in hospitals are a rapidly diffusing innovation (Figure 1) and have been shown to both improve quality and reduce costs of care for America's sickest and most complex patients- a group at high risk for pain, suffering, and fragmented unreliable medical care that fails to meet their most fundamental needs. The chronically and seriously ill constitute only 5-10% of our patients, but account for well over half of the nation's healthcare costs. Palliative care programs are a solution to this growing quality and cost crisis.

Why palliative care? Despite enormous expenditures, studies demonstrate that patients with serious illness and their families receive poor quality medical care, characterized by untreated pain and other symptoms, unmet personal care needs, high caregiver burden, and low patient and family satisfaction.[1-4] Of the $432 billion spent by Medicare in 2007, 30% ($186 billion) was spent on acute care (hospital) services and a very small proportion – 5% -- of the sickest Medicare beneficiaries account for fully 44% of total program spending.[3,46] Similarly, of the $272.6 billion spent by Medicaid in 2004, 76% (207.8 billion) was spent on acute care (hospital) services and a very small proportion – 4% – of the sickest Medicaid beneficiaries account for fully 48% of total program spending.[3] This small but disproportionately ill subset of the nation's patients are the target population for palliative care services.

What is palliative care and how does palliative care differ from hospice?

As defined by CMS, ***Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.*** [41]

Non-hospice palliative care is appropriate at any point in a serious illness. It is provided at the same time as life-prolonging treatment. There is no prognostic requirement, and no need to choose between life prolonging and palliative treatment approaches.

Hospice is a form of palliative care that provides care for those in the last weeks-few months of life. Hospice-eligible patients must have a 2 MD-certified prognosis of less than 6 months and give up insurance coverage for curative treatment in order to access hospice services.

How does palliative care improve care quality? Palliative care programs address pain and symptoms that cause untold human misery and are the number one concern of patients living with chronic illness.[40] As in my patient described above, pain and other distressing symptoms have been shown to increase hospital complications and lengths of stay, and many studies have demonstrated poor to non existent communication between patients, families, and physicians about the disease, the treatment options and what to expect. Palliative care teams provide expert treatment of pain and other symptoms, meet with patients, families, and physicians to establish clear and feasible care goals, address care alternatives including withdrawing or not initiating treatments that don't meet those goals, and develop safe and effective discharge plans for these medically complex patients. Through these methods. palliative care programs improve the quality of medical care received by our sickest patients while reducing hospital costs, readmissions, and emergency department visits. Typically delivered by an interdisciplinary consultation team working in concert with the patient's primary physician, hospital palliative care programs provide highly specialized and expert care to patients with the most serious and complex illness.

Research demonstrates that palliative care programs improve physical and psychological symptoms (Figure 2)[34], caregiver well-being (Table 1), and consulting physician satisfaction (Figure 4).[7-17,34] Employing interdisciplinary teams of physicians, nurses, social workers, and additional personnel when needed (chaplains, physical therapists, psychologists), palliative care teams identify and rapidly treat distressing symptoms which have been independently shown to impede recovery, increase confusion and delirium, and lengthen hospitalizations (Figure 3).[10,16,17] Palliative care team members meet and talk extensively with patients and their families to make sure they understand their illness and what it means, support families in crisis, and plan for safe transitions out of hospitals to lower intensity community settings that are preferred by patients and families in the overwhelming majority of cases.[42] ((Table 1). Finally, because of the assistance that they provide to already time-pressured physicians, palliative care programs are valued and heavily utilized by referring physicians (Figure 4).

How does palliative care promote patient-centered care while reducing healthcare costs?

Palliative care is genuinely patient centered because it begins with the goals and preferences of the patient and family, and, as in the case of Mrs. J, supports development of a realistic care plan that meet these goals. Health care costs are reduced because seriously ill patients are able to leave the hospital and receive care in settings more appropriate to their needs- often in the place where more than 90% of patients say they want to be- at home. This is possible because palliative care teams ensure the necessary level of professional medical and nursing support for family members providing direct care to the patient after hospital discharge. Successful transition management requires expert and effective care coordination, and reliable access to sophisticated support from home care and hospice agency referrals. Had hospice not been available to Mrs. J in her nursing home, we could not have assured the pain management expertise so critical to her wound care and healing process. In addition, when a patient with advanced illness turns to an emergency department for help, they can be admitted and cared for directly by the hospital palliative care specialists best able to address their needs, instead of defaulting to a critical care setting as occurred in Mrs. J's case; hence more patients with advanced chronic illness are admitted directly to the palliative care service instead of a high cost ICU bed; patients not benefiting from an ICU setting are transferred out to more appropriate and lower intensity settings; and non-beneficial, potentially harmful, or futile imaging, laboratory, specialty consultation, drugs and procedures are avoided (Figure 5).[37].

Studies of a range of palliative care interventions from Europe, Canada, Australia, and the U.S. demonstrate consistent improvement in pain and other symptoms, patient and family satisfaction, and likelihood of receiving care in the place of choice.[34] Research from Europe in which patients were randomized to usual care or palliative care[7,11,12,17] (studies that would be impossible to perform in the U.S.) and single- and multisite observational studies in the U.S. also demonstrate that the efficiency associated with palliative care can be substantial.[21-26,34,37] In a recently published study[37] of 8 U.S. hospitals serving low, medium, and high cost markets, seriously ill patients receiving hospital palliative care consultation and compared to matched patients who received usual care, had an adjusted net per admission savings of $1,696 for patients discharged alive, and $4,908 for patients who died (Table 2).

Essential elements of quality palliative care. Palliative care is not hospice[5]. Until recently, palliative care services were typically available only to patients enrolled in hospice. Now, palliative care programs are found increasingly in hospitals – the main site of care for the seriously ill and site of death for 50% of adults on average nation-wide. As of 2006, 30% of U.S hospitals and over 70% of hospitals with more than 250 beds reported the presence of a palliative care program – an increase of 96% from 2000 (Figure 1).[6,33,35] As outlined (Table 3) by the National Quality Forum[27] and the National Consensus Project for Quality Palliative Care[5], the essential structural elements of hospital palliative care programs include:

- Interdisciplinary team of clinical staff (MD, RN and SW)
- Staffing ratios determined by hospital size
- Staff trained, credentialed and/or certified in palliative care
- Access and responsiveness 24 hours per day, 7 days per week

Based on the National Quality Forum's Framework and Preferred Practices for Hospice and Palliative Care released in 2006.[27,38] The Joint Commission has developed a new Palliative Care Certificate Program to be offered in the Autumn of 2008.[43] This mechanism will stimulate development of standardized and reliably high quality palliative cervices in America's hospitals through adherence to existing quality guidelines.

Access to palliative care: Recent data[35] demonstrate large variability in access to palliative care in U.S. hospitals. As in many other aspects of our health care system, where you live matters. An analysis of hospitals with more than 50 beds (larger hospitals are where most Americans receive care) found that 53% reported a palliative care program on the 2006 annual hospital survey administered by the American Hospital Association. Over 80% of the nation's medical schools report an association with a teaching hospital palliative care program, creating at least the potential for effective education of the next generation of physicians and other health care providers. However, considerable state by state variation was observed. Aside from location, factors increasing likelihood of a palliative care program include larger hospital size, teaching hospital status, higher educational level in the community, and the presence of a hospital-owned hospice program. Factors associated with lower likelihood of a palliative care program include smaller hospital size, for-profit ownership status, and public or sole community provider status. This study also suggests that states with higher palliative care program penetration had fewer hospital deaths, fewer patients requiring ICU admissions, and, as a result, lower overall expenditure per Medicare beneficiary.[35] A detailed state-by-state report card on access to palliative care may be found at www.capc.org/reportcard.

What prevents equitable access to quality palliative care? Barriers preventing equitable access to quality palliative care for America's seriously ill citizens include: 1) Lack of an adequate evidence base to guide rigorous quality care at the bedside; 2) lack of medical and nursing school teaching faculty needed to train the next generation in the core competencies of palliative care (such as assessment and treatment of pain and other symptoms); and 3) an inadequate workforce pipeline to meet the palliative care needs of America's seriously ill patients because of lack of support for graduate medical and nursing education in palliative care.

The research gap: Despite the fact that each one of us will eventually get sick and die, almost no federal support for research aimed at improving the quality of life during chronic and serious illness has been available to develop the evidence base necessary to relieve suffering and reliably help patients and families in need. Mrs. J's doctors' fear of using opioid analgesics in elderly patients was based on myths that recent research has finally debunked- multiple studies have now shown that contrary to what most of us were taught, it is untreated pain that causes confusion, and treatment and prevention of pain actually reduces the risk of delirium. A recent study found that less than one half of one percent of all NIH dollars was used to support research on improving the quality of life during a serious illness.[38] Those NIH Institutes most qualified to invest in palliative care research because of their size, budget, and disease focus (including NCI, NHLBI, NIDDK, NIA) have for the most part, failed to do so. *NIH funding specifically designated for support of research in palliative care is necessary to correct this imbalance in NIH priorities.*

Faculty development: The training of future generations of front line health care providers is entrusted to the faculty in the nation's medical and nursing schools. The poor quality of care experienced by the seriously ill in this country (high symptom burden, poor doctor patient communication, widespread fragmentation and inefficiency) is directly attributable to a near total lack of medical and nursing education in palliative care. During 9 years of medical education after college- (4 years of medical school, 3 years of internal medicine, and 2 years of geriatrics training) I did not receive a single lecture on pain management, treatment of other symptoms like shortness of breath or nausea, or how to communicate bad news and discuss goals of care with patients and their families. Most regular non-medical people find this difficult to believe- how can it be true that doctors and nurses are not taught how to manage pain? But it is true, and this is major reason for the poor quality of care reported by patients and their families. This has begun, very slowly, to change as medical schools try to make room in their crowded curricula for these fundamental aspects of patient care-, but the persistent barrier to providing such teaching is the need for expert palliative care faculty educators. Such education cannot take place without a cadre of teaching faculty at all of the nation's medical and nursing schools. A mechanism for support of medical and nursing faculty in palliative care is needed. *A model similar to that employed to improve the geriatrics faculty workforce (HRSA's Geriatric Academic Career Awards - GACA) is necessary to create the palliative care teaching faculty prerequisite to an adequately trained healthcare workforce. A proposed model for Palliative Care Academic Career Awards* (PACA) *has been developed.*[44]

Workforce pipeline: The largest impediment to delivery of palliative care across our nation is the lack of professionals specifically trained to do this work. Hospitals and medical schools are all competing for the same few well trained palliative care professionals to lead and staff their programs, teach their students, and assure quality of care to the seriously ill. In 2006 the American Board of Medical Specialties did approve palliative medicine as a new medical specialty under 10 parent boards, including internal and family medicine, surgery, and pediatrics. The first American Board of Internal Medicine administered board certification examination will be given in November 2008. The Accreditation Council for Graduate Medical Education (ACGME) followed with approval of subspecialty graduate medical fellowship training programs in palliative medicine. Despite these major strides, the cap on Graduate Medical Education (GME) dollars imposed on teaching hospitals under the Balanced Budget Act of 1997[45] means that there is no funding to support specialty training in palliative medicine. Without support for graduate medical (and nursing) education in palliative medicine, there is no workforce to lead clinical programs in America's hospitals, no faculty to teach future generations of providers, and no clinical researchers to improve the quality of our care. It is unrealistic to expect teaching hospitals to support graduate palliative medicine trainees by eliminating other badly needed training positions, and it has not occurred. The result is that few training slots for specialty palliative medicine are available in the U.S. at this time, and most of these are insecurely funded by philanthropy. *The solution to the physician workforce deficit is an* *exemption to the cap on GME slots for teaching hospitals offering ACGME-accredited palliative medicine training programs. Training programs targeted to masters-prepared nurses and nurse practitioners (perhaps through HRSA funding) are another key solution to the workforce deficit.*

When I broadened my career focus from geriatrics to include palliative medicine in 1995 I did not know how we would address the problems facing patients like Mrs. J- just that we had to figure out a way and do something to make things better. In large part thanks to enormous investments from charitable foundations (such as the Robert Wood Johnson Foundation, John A. Hartford Foundation, Open Society Institute and others), who contributed over 250 million dollars to building the field between the late 80's through the present, substantial progress has been made. Hospital palliative care programs are present in the majority of hospitals with more than 50 beds. Palliative medicine is a new medical subspecialty. Young people completing their training in medicine and nursing can now choose palliative care as a career path. We have come a long way in a short period of time. For palliative care to become an integral and reliable component of the U.S. healthcare system, however, will require some help from you.

Thank you for your interest in our work in palliative care.

Figure 1: Can Patients Access Hospital Palliative Care Programs? Growth in Number between 2000-2006

(Source: AHA Annual Survey)

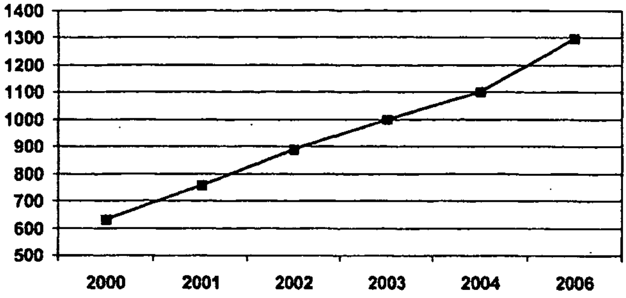


Figure 2

Palliative Care Improves Patient Care

- Mortality follow back survey palliative care vs. usual care
- N=524 family survivors
- Overall **satisfaction markedly superior** in palliative care group, p<.001
- Palliative care superior for:
  - ➢ emotional/spiritual support
  - ➢ information/communication
  - ➢ care at time of death
  - ➢ access to services in community
  - ➢ well-being/dignity
  - ➢ care + setting concordant with patient preference
  - ➢ pain
  - ➢ PTSD symptoms

Casarett et al. J Am Geriatr Soc 2008;56:593-99.

Figure 3: Symptom Improvement Following Palliative Care Consultation at Mount Sinai Hospital in New York, NY.

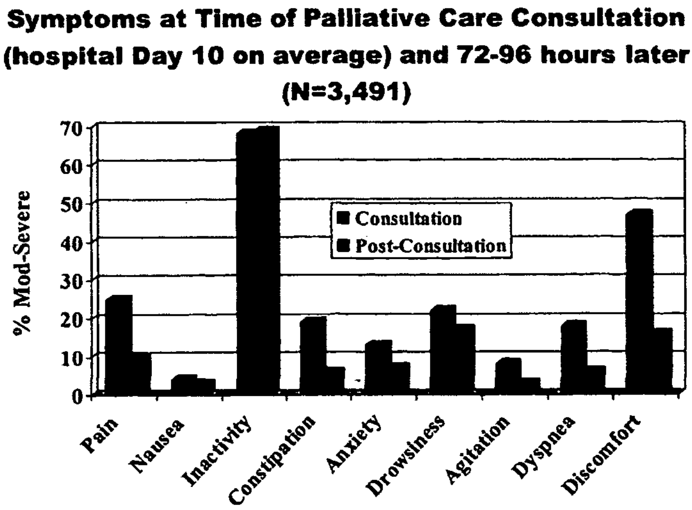


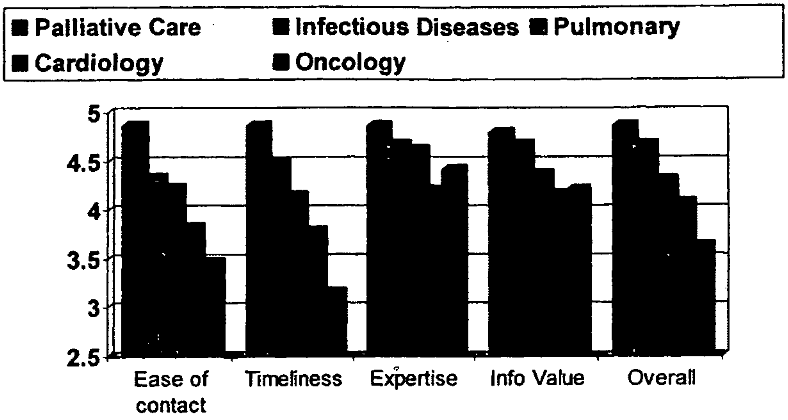
Table 1: Effect of Palliative Care on Family Satisfaction and Family Needs*

	Palliative Care	Usual Care	P
Religious and spiritual beliefs addressed	46%	24%	.004
Enough support for their own feelings	73%	55%	.04
Confident that they knew what to do when patient died	87%	71%	.03
Received referral for psychosocial support	36%	14%	.002

*Adjusted for: Patient age, race (white versus nonwhite), diagnosis, bed-bound, insurance (Medicaid versus non-Medicaid) and if died in ICU

Gelfman LP, Meier DE, Morrison RS. Does palliative care improve quality? A survey of bereaved family members. J Pain Sympt Manage 2008 Apr 12;

Figure 4: Physician Satisfaction with Internal Medicine Consultation Services (range 1-5)

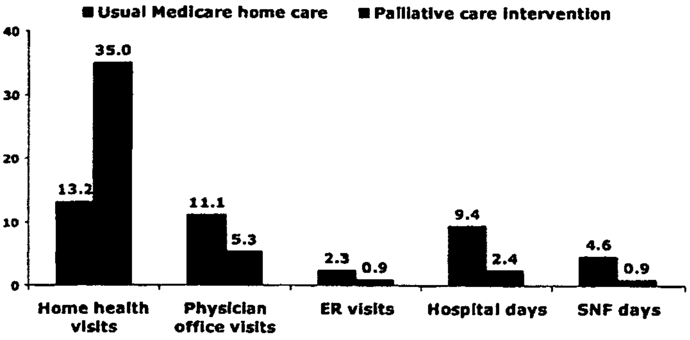


Source: MCW Froedert Hospital Medical Staff Survey, Milwaukee, WI, 2007

Figure 5

Palliative Care Shifts Care Out of Hospital to Home

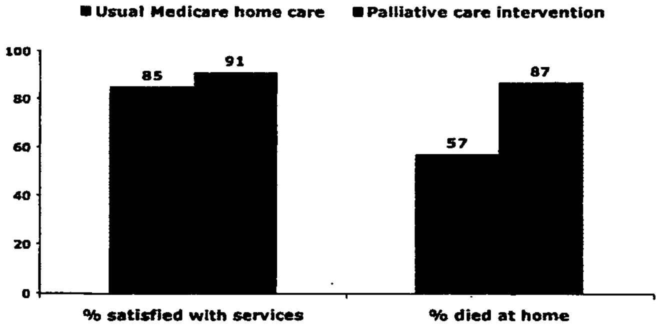
Service Use Among Patients Who Died from CHF, COPD, or Cancer Palliative Home Care versus Usual Care, 1999–2000



Brumley, R.D. et al. 2003. *The Permanente Journal* 7(2):7–12.

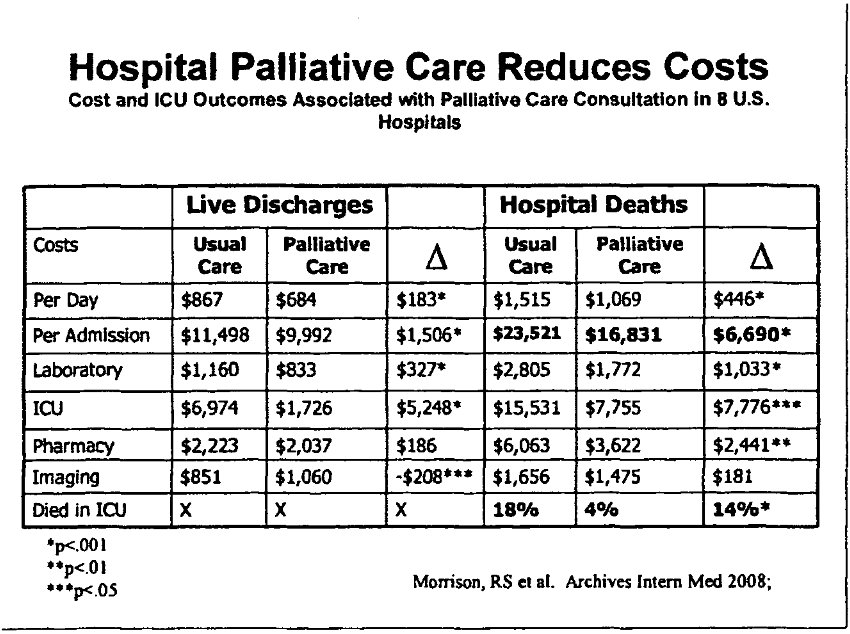
Palliative Care Allows People to Die at Home instead of Hospital

Outcomes Among Patients Who Died from CHF, COPD, Cancer Palliative Care versus Usual Care, 1999–2000



Brumley, R.D. et al. 2003. *The Permanente Journal* 7(2):7–12.

Table 2



Hospital Palliative Care Reduces Costs

Cost and ICU Outcomes Associated with Palliative Care Consultation in 8 U.S. Hospitals

	Live Discharges			**Hospital Deaths**		
Costs	**Usual Care**	**Palliative Care**	Δ	**Usual Care**	**Palliative Care**	Δ
Per Day	$867	$684	$183*	$1,515	$1,069	$446*
Per Admission	$11,498	$9,992	$1,506*	**$23,521**	**$16,831**	**$6,690***
Laboratory	$1,160	$833	$327*	$2,805	$1,772	$1,033*
ICU	$6,974	$1,726	$5,248*	$15,531	$7,755	$7,776***
Pharmacy	$2,223	$2,037	$186	$6,063	$3,622	$2,441**
Imaging	$851	$1,060	-$208***	$1,656	$1,475	$181
Died in ICU	X	X	X	**18%**	**4%**	**14%***

*p<.001
**p<.01
***p<.05

Morrison, RS et al. Archives Intern Med 2008;

Table 3: NQF Preferred Practices for Palliative Care[27]

A National Framework and
Preferred Practices for Palliative
and Hospice Care Quality
A National Quality Forum (NQF) Consensus Report

The National Quality Forum has recently identified palliative care and hospice care as national priority areas for healthcare quality improvement. The highly influential NQF report provides a framework and set of NQF-endorsed™ preferred practices that focus on improving palliative care and hospice care across the Institute of Medicine's six dimensions of quality – safe, effective, timely, patient-centered, efficient, and equitable. The preferred practices mark a crucial step in the standardization of palliative care and hospice.

Preferred Practices...

1. Provide palliative and hospice care by an **interdisciplinary team** of skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors, and others who collaborate with primary healthcare professional(s).
2. Provide access to palliative and hospice care that is responsive to the patient and family **24 hours a day, 7 days a week**.
3. Provide **continuing education** to all healthcare professionals on the domains of palliative care and hospice care.
4. Provide adequate **training and clinical support** to assure that professional staff is confident in their ability to provide palliative care for patients.
5. Hospice care and specialized palliative care professionals should be appropriately **trained, credentialed, and/or certified** in their area of expertise.
6. Formulate, utilize, and regularly review a **timely care plan** based on a comprehensive interdisciplinary assessment of the values, preferences, goals, and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care.
7. Ensure that upon transfer between healthcare settings, there is timely and thorough communication of the patient's goals, preferences, values, and clinical information so that **continuity of care and seamless follow-up** are assured.
8. Healthcare professionals should present **hospice as an option** to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.
9. Patients and caregivers should be asked by palliative and hospice care programs to assess physicians'/healthcare **professionals' ability to discuss hospice** as an option.
10. **Enable patients to make informed decisions** about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.
11. Provide **education and support to families** and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.
12. Measure and **document pain, dyspnea, constipation, and other symptoms** using available standardized scales.
13. Assess and **manage symptoms and side effects** in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
14. Measure and **document anxiety, depression, delirium, behavioral disturbances,** and other common psychological symptoms using available standardized scales.
15. **Manage anxiety, depression, delirium, behavioral disturbances,** and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.

16. Assess and **manage the psychological reactions** of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss.
17. Develop and offer a **grief and bereavement care plan** to provide services to patients and families prior to and for at least 13 months after the death of the patient.
18. Conduct regular **patient and family care conferences** with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.
19. Develop and implement a comprehensive **social care plan** that addresses the social, practical, and legal needs of the patient and caregivers, including but not limited to relationships, communication, existing social and cultural networks, decision making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.
20. Develop and document a plan based on an assessment of **religious, spiritual, and existential concerns** using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.
21. Provide information about the **availability of spiritual care services,** and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships.
22. Specialized palliative and hospice care teams should **include spiritual care professionals** appropriately trained and certified in palliative care.
23. Specialized palliative and hospice spiritual care professionals should build **partnerships with community clergy** and provide education and counseling related to end-of-life care.
24. Incorporate **cultural assessment** as a component of comprehensive palliative and hospice care assessment, including but not limited to locus of decision making, preferences regarding disclosure of information, truth telling and decision making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering, and grieving, and funeral/burial rituals.
25. Provide professional **interpreter services** and culturally sensitive materials in the patient's and family's preferred language.
26. Recognize and **document the transition to the active dying phase,** and communicate to the patient, family, and staff the expectation of imminent death.
27. **Educate the family on a timely basis regarding the signs and symptoms of imminent death** in an age-appropriate, developmentally appropriate, and culturally appropriate manner.
28. As part of the ongoing care planning process, routinely ascertain and **document patient and family wishes** about the care setting for the site of death, and fulfill patient and family preferences when possible.
29. Provide **adequate dosage of analgesics and sedatives** as appropriate to achieve patient comfort during the active dying phase, and address concerns and fears about using narcotics and of analgesics hastening death.
30. **Treat the body after death with respect** according to the cultural and religious practices of the family and in accordance with local law.
31. Facilitate effective grieving by implementing in a timely manner a **bereavement care plan** after the patient's death, when the family remains the focus of care.
32. **Document the designated surrogate/decision maker** in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.
33. **Document the patient/surrogate preferences for goals of care,** treatment options, and setting of care at first assessment and at frequent intervals as conditions change.
34. **Convert the patient treatment goals into medical orders,** and ensure that the information is transferable and applicable across care settings, including long-term care, emergency

medical services, and hospital care, through a program such as the Physician Orders for Life-Sustaining Treatment (POLST) program.

35. **Make advance directives and surrogacy designations available across care settings,** while protecting patient privacy and adherence to HIPAA regulations, for example, by using Internet-based registries or electronic personal health records.

36. Develop healthcare and community collaborations to **promote advance care planning** and the completion of advance directives for all individuals, for example, the Respecting Choices and Community Conversations on Compassionate Care programs.

37. Establish or have access to **ethics committees or ethics consultation** across care settings to address ethical conflicts at the end of life.

38. **For minors with decision making capacity, document the child's views and preferences** for medical care, including assent for treatment, and give them appropriate weight in decision making. Make appropriate professional staff members available to both the child and the adult decision maker for consultation and intervention when the child's wishes differ from those of the adult decision maker.

Order a copy of the NQF Consensus Report online.
Go to www.qualityforum.org/publications/reports

Distributed courtesy of the National Consensus Project.

REFERENCES

1. Field MJ, Cassel CK, eds. *Approaching death: improving care at the end of life*. Washington, D.C.: National Academy Press; 1997.
2. Thorpe KE, Howard DH. The rise in spending among Medicare beneficiaries: the role of chronic disease prevalence and changes in treatment intensity. *Health Aff (Millwood).* Sep-Oct 2006; 25(5):w378-388.
3. Henry J. Kaiser Family Foundation. Kaiser Commission on Medicaid Facts: Medicaid and the Uninsured. Available at: http://www.kff.org/medicaid/upload/7565.pdf. Accessed July 30, 2007.
4. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA.* Jan 7 2004;291(1):88-93.
5. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care.* New York 2004.
6. American Hospital Association. *AHA Hospital Statistics*. Chicago: American Hospital Association; 2007.
7. Higginson IJ, Finlay IG, Goodwin DM, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage.* Feb 2003;25(2):150-168.
8. Smith TJ, Staats PS, Deer T, et al. Randomized clinical trial of an implantable drug delivery system compared with comprehensive medical management for refractory cancer pain: impact on pain, drug-related toxicity, and survival. *J Clin Oncol.* Oct 1 2002;20(19):4040-4049.
9. Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. *Arch Intern Med.* Jan 12 2004;164(1):83-91.
10. Manfredi PL, Morrison RS, Morris J, Goldhirsch SL, Carter JM, Meier DE. Palliative care consultations: how do they impact the care of hospitalized patients? *J Pain Symptom Manage.* 2000;20(3):166-173.
11. Jordhoy MS, Fayers P, Loge JH, Ahlner-Elmqvist M, Kaasa S. Quality of life in palliative cancer care: results from a cluster randomized trial. *J Clin Oncol.* Sep 15 2001;19(18):3884-3894.
12. Ringdal GI, Jordhoy MS, Kaasa S. Family satisfaction with end-of-life care for cancer patients in a cluster randomized trial. *J Pain Symptom Manage.* Jul 2002;24(1):53-63.
13. Lilly CM, De Meo DL, Sonna LA, et al. An intensive communication intervention for the critically ill. *The American Journal of Medicine.* 2000/10/15 2000;109(6):469-475.
14. Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet.* 2004;363:312-319.
15. Fellowes D, Wilkinson S, Moore P. Communication skills training for health care professionals working with cancer patients, their families and/or carers (Cochrane Review). *The Cochrane Library.* Chichester, UK: John Wiley & Sons, Ltd.; 2004.
16. Morrison RS, Magaziner J, McLaughlin MA, et al. The impact of post-operative pain on outcomes following hip fracture. *Pain.* Jun 2003;103(3):303-311.
17. Jordhoy MS, Fayers P, Saltnes T, Ahlner-Elmqvist M, Jannert M, Kaasa S. A palliative-care intervention and death at home: a cluster randomised trial. *Lancet.* 2000;356(9233):888-893.

18. Rubin DB. Estimating causal effects from large data sets using propensity scores. *Ann Intern Med.* 1997;127:757-763.

19. Rubin DB. Using Propensity Scores to Help Design Observational Studies: Application to the Tobacco Litigation. *Health Services & Outcomes Research Methodology.* 2001;2:169-188.

20. Rubin DB, Thomas N. Matching using estimated propensity scores: relating theory to practice. *Biometrics.* Mar 1996;52(1):249-264.

21. Back AL, Li Y-F, Sales AE. Impact of Palliative Care Case Management on Resource Use by Patients Dying of Cancer at a Veterans Affairs Medical Center. *Journal of Palliative Medicine.* 2005;8(1):26-35.

22. Smith TJ, Coyne P, Cassel B, Penberthy L, Hopson A, Hager MA. A high-volume specialist palliative care unit and team may reduce in-hospital end-of-life care costs. *J Palliat Med.* Oct 2003;6(5):699-705.

23. Elsayem A, Swint K, Fisch MJ, et al. Palliative care inpatient service in a comprehensive cancer center: clinical and financial outcomes. *J Clin Oncol.* May 15 2004;22(10):2008-2014.

24. Carlson RW, Devich L, Frank RR. Development of a comprehensive supportive care team for the hopelessly ill on a university hospital medical service. *Jama.* 1988;259(3):378-383.

25. Morrison RS, Cassel JB, Caust-Ellenbogen M, Spragens L, Meier D. Substantial Cost Savings Associated with Hospital-Based Palliative Care Programs. *J Amer Geriatr Soc.* 2007;44(S1):S7.

26. Penrod JD, Deb P, Luhrs C, et al. Cost and utilization outcomes of patients receiving hospital-based palliative care consultation. *J Palliat Med.* Aug 2006;9(4):855-860.

27. National Quality Forum (NQF), *National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*, Washington DC: NQF; 2006.

28. Tu JV, Bowen J, Chiu M et al. Effectiveness and safety of drug-eluting stents in Ontario. *N Engl J Med* 2007;357:1393-402.

29. Gill SS, Bronskill SE, Normand S-L, et al. Antipsychotic drug use and mortality in older adults with dementia. *Ann Intern Med* 2007;146:775-786.

30. Johnstone J, Marrie TJ, Eurich DT, Mujumdar SR. Effect of pneumococcal vaccine in hospitalized adults with community-acquired pneumonia. *Arch Intern Med* 2007;167:1938-43.

31. Vaughan-Sarrazin MS, Wakefield B, Rosenthal GE. Mortality of Department of Veterans Affairs patients undergoing coronary revascularization in private sector hospitals. *HSR: Health Services Research* 2007;42:1802-1821.

32. Fu AS, Jiang JZ, Reeves JH et al. Potentially inappropriate medication use and healthcare expenditures in the US community-dwelling elderly. *Med Care* 2007;45:472-476.

33. Morrison RS, Maroney-Galin C, Kralovec PD, Meier DE. The growth of palliative care programs in United States hospitals. *J Palliat Med* 2005; 8(6):1127-34.

34. Casarett D, Pickard A, Bailey FA, Ritchie C, Furman C, Rosenfeld K, Shreve S, Chen Z, Shea JA. Do palliative care consultations improve patient outcomes? J Am Geriatr Soc 2008;56:593-9

35. Goldsmith BA, Dietrich J, Du Q, Morrison RS. Variability in access to hospital palliative care in the United States. J Palliat Med 2008;11:1-9.

36. Gelfman LP, Morrison RS. Research funding for palliative medicine. J Palliat Med 20008;11:36-43.
37. Morrison RS, Penrod JD, Cassel JB, Caust-Ellenbogen M, Litke A, Spragens L, Meier DE. Cost savings associated with US hospital palliative care consultation programs. Arch Intern Med 2008;168:1783-90
38. Ferrell B, Paice J, Koczywas M. New standards and implications for improving the quality of supportive oncology practice. J Clin Oncol 2008;26:3824-31
39. Gelfman LP, Meier DE, Morrison RS. Does palliative care improve quality? A survey of bereaved family members. J Pain Sympt Manage 2008 Apr 12; :
40. Singer PA, Martin DK, Kelner M. Quality end of life care: patients' perspectives. JAMA 1999;281:163-8.
41. *73 FR 32204, June 5, 2008 Medicare Hospice Conditions of Participation – Final Rule*
42. Pritchard RS, Fisher ES, Teno JM, Sharp SM, Reding DJ, Knaus WA, Wennberg JE, Lynn J. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. J Am Geriatr Soc. 1998 Oct;46(10):1242-50.
43. http://www.jointcommission.org/CertificationPrograms/HCS/ accessed Sept. 19, 2008
44. http://www.ilcusa.org/pages/publications/financing-longevity/palliative-care-academic-career-awards-a-public-private-partnership-to-improve-care-for-the-most-vulnerable.php. accessed Sept. 19, 2008
45. Salsberg E, Rockey PH, Rivers KL, Brotherton SE, Jackson GR. US residency training before and after the 1997 BBA. JAMA 2008; 300:1174-80.
46. http://www.medpac.gov/documents/Jun08DataBook_Entire_report.pdf accessed Sept. 19, 2008

Senator WHITEHOUSE. Dr. Teno.

STATEMENT OF DR. JOAN TENO, PROFESSOR OF COMMUNITY HEALTH AND MEDICINE, WARREN ALPERT SCHOOL OF MEDICINE, BROWN UNIVERSITY, PROVIDENCE, RI

Dr. TENO. Good morning. I want to thank you for the opportunity to speak to the needs of older Americans dying in nursing homes. My name is Dr. Joan Teno. I'm a Professor of Community Health and Medicine at the Warren Alpert School of Medicine.

Senator WHITEHOUSE. Dr. Teno, could you hold the microphone a little bit closer? Everybody will hear better if you do.

Dr. TENO. Ok, how's this? I've had the privilege of being involved in more than 150 publications, numerous grant awards, yet if you search my name using the Google search engine, the headline associated with my name is cat predicts death in nursing home. Indeed, in Rhode Island, we have a cat named Oscar who lives at the Steere House Nursing home who regularly holds vigils with people dying from dementia on the locked dementia unit.

We wrote a short piece that was published in the Newman Journal by a friend of mine, Dr. David Dosa and that piece trans-global. Who would imagine that Oscar the cat, the cat that sits with people dying from dementia would become the topic of coffee breaks and would be the discussion at dinner tables? This experience illustrates what a touch tone issue dying in nursing homes are for so many people across the United States.

Today I'd like to speak to you about the importance of nursing homes in end of life care, the opportunities to improve, evidence that we can improve and suggest solutions for consideration of Congress.

First, nursing homes are the final place of care in sight of death for one in four Americans. Forty percent of persons who die spend some time in a nursing home in their last months of life. Nursing homes are the last safety net for an impoverished elderly who can't afford care needed to remain at home. Many don't have families and high quality nursing homes, such as the one that Oscar the cat lives, the nursing home staff become the sole source of love and care for these older people.

Yet there are important opportunities to improve. In a nationwide study that I conducted while at Brown University, we found that one in three bereaved family members reported the need for better pain control in a nursing home. They did not have enough emotional support. They stated that their loved one was not treated with dignity.

Only 42 percent rated the care of their loved one as excellent compared to 70 percent of those persons dying with hospice services. Sadly, nursing home residents are often lost in between transition between an acute care hospital and a nursing home. They're sort of lost there going back and forth.

Let me just give you some numbers to illustrate that. In the United States, the rate of healthcare transitions in the last 6 months of life for people residing in a nursing home varies from a low of 1.9 in Salem, OR to a high of 5.1 transitions per person in Monroe, LA. So that means almost every 30 days someone's moving to a different location. But most of those movements probably is in the last several weeks of life.

Such transitions are costly, can often be avoided and lead to interventions that many would classify as futile. The key to decreasing this rate of healthcare transition is promoting advance care planning. A process of communication that clarifies patient preferences and formulates a plan of care that ensures those wishes will be honored.

The good news is we can improve. Let me tell you about the experience in Rhode Island. In Rhode Island, we became focused on the fact that one in seven nursing home residents had persistent or severe pain. A community, state, government partnership in Rhode Island achieved a 43 percent reduction in severe pain. This effort would not have been possible without the Attorney General's Task Force at End of Life Care created by Senator Whitehouse, then Attorney General of Rhode Island.

Finally, let me leave you with some proposed solutions for consideration of Congress.

First, a key step to decreasing the weight of costly, but burdensome healthcare transitions are to promote advanced care planning. Obviously this needs to be done at a community level.

Second, Congress should assure there are sufficient number of physicians with needed training and skills in hospice and palliative medicine.

Third, we need to tackle the issue of reducing healthcare transition through promoting advance care planning. Fostering hospital/nursing home partnership is one way forward. There's some very good evidence coming out of Sacramento that will demonstrate that partnerships between the hospitals and nursing homes can improve, not only the quality of life, but also reduce terminal hospitalizations. The bottom line is hospitals need to take a leadership role.

Fourth, the current Medicare and Medicaid service ruling that will cut hospice reimbursement by 5.5 billion dollars should be rescinded. I urge your support of the Medicare Hospice Protection Act. Furthermore, I would urge you to expand the role of hospice in a cost neutral manner.

The hospice benefit was created around the dying trajectory of people dying of cancer. Now increasingly dementia is the fifth leading cause of death in the United States. We need to assure that those persons and their families afflicted with dementia have the same access to palliative care as those people dying of cancer. The current financial incentives under Medicare result in multiple, costly hospitalizations. This expansion should be done in a manner that guarantees high quality care through appropriate regulatory oversight and public reporting of hospice quality.

As one elderly woman wrote to us in an email message, she hoped she would die in a nursing home with a cat on her bed. Our hope is policymakers will recognize the importance of adequate funding so that a hospice nurse, social worker, spiritual counselor and a volunteer can be at that person's bedside, who must adequately fund and demand high quality care for frail, older Americans who's last home is a nursing home. I thank you for the opportunity to speak with you today.

[The prepared statement of Dr. Teno follows:]

Joan M Teno, M.D., M.S.

Professor of Community Health and Medicine

The Warren Alpert School of Medicine of Brown University

Testimony for the Senate Special Committee on Aging

Honoring Final Wishes: How to Respect American's Choices at the End of Life

September 24, 2009

Good Morning.

I want to thank you for the chance to speak to you about the needs of older dying Americans. My name is Dr. Joan Teno. I am a Professor of Community Health and Medicine at the Warren Alpert School of Medicine of Brown University. Also, I serve in the role of chair of the Quality & Research Strategic Coordinating Committee of the American Academy of Hospice and Palliative Medicine, the physician specialty society representing more than 3.400 health professionals dedicated to hospice and palliative medicine. For the past two decades, I have had the privilege of conducting research and providing medical care to countless seriously ill and dying persons through my work with Home and Hospice Care of Rhode Island. I have more than 150 publications and numerous grants funded by the National Institute of Aging, the National Cancer Institute and the Robert Wood Johnson Foundation. Yet, if you search my name using Google search engine, the news headline associated with my name is "Cat Predicts Death in Nursing Home." Oscar is a cat that lives in a dementia unit at a RI nursing home that apparently regularly holds death vigils with persons dying from dementia. A short story by my colleague, Dr. David Dosa, that described this process in the New England Journal of Medicine[1] went "transglobal" and led to Oscar's appearances on every major US news network, the BBC, and multiple foreign media outlets. A cat that sits with nursing home residents dying from dementia became the talk of coffee breaks and the dinner tables throughout America. We received countless e-mail messages that spoke of concerns about dying in a nursing home. Indeed, a survey of older persons found the majority of persons would "rather die" than live in a nursing home. Often, person stated in their email messages to us if they could not die at home, they wanted to die at a nursing home with a cat like Oscar. This experience illustrates what a touchstone issue dying in nursing homes are for many people across the country.

Central to improving end of life care in nursing homes is a fundamental first step of promoting patient's choice through advance care planning. Advance care planning is more than just the completion of a written advance directive; rather it is an ongoing communication between a health care provider and a patient that accomplishes two important goals. First, the patient goals and values are clarified often resulting in the completion of a written advance directive. Second, a care plan is created to ensure that the patient's wishes are honored. As I learned early in my medical care while caring for a dying patient just blocks away from the White House, completing and documenting an written advance directive that states that the patient wants to die at home is not enough. As a physician, I must anticipate the problems that may arise in the middle of night and ensure there is adequate medication to provide for that dying patient's comfort. At that time, not many pharmacies were willing to deliver drugs such as morphine in the middle of the night, even just a few blocks away from the White House. Today, I would like to speak with you about the importance of nursing homes in caring for persons at the close of life, the opportunities to improve that care, the evidence that we can improve it, and suggest solutions for the consideration of Congress.

The Evolving Role of Nursing Homes

Nursing homes are the final place of care and site of death for a growing number of Americans. One in four Americans die in a nursing home[2] and nearly 40% were in a nursing home during their last month of life.[3] Nursing homes are the last safety net for impoverished elderly who can't afford the care needed to remain at home. Many don't have families. In high quality nursing homes such as the one that Oscar the cat lives, the nursing home staff – nurses, social workers, physicians, maintenance workers, dieticians, physical therapists and others – can become the sole sources of love and care for these frail, older persons as they die.

The Opportunity to Improve

While most parts of the health care system can improve, the salience of this need for the thousands of frail elderly who die in nursing homes cannot be overstated. In a study we conducted of survivors of individuals who had been in a nursing home in their last weeks of life, we found about one in three people reported the need for better pain control, that they did not have enough emotional support, and stated that their loved one was not treated with dignity. Only 42% rated the care of their loved one as excellent compared to 70% for those persons dying at home with hospice services. [3] Behind these rates lie compelling stories of the urgency and need to improve.

> *As long as somebody was there with [my father], it was fine. And the minute we left, then he was about totally ignored. I went [out] for lunch one day...and came back and they had him in the hall, strapped in a chair, completely slumped over. And, evidently, he had, tried to get out of bed or something and they didn't, they were busy and they didn't feel like they had time to watch him. But he was not properly clothed, and my opinion was at that point they saw him as nothing but an old man. And we had that same experience in the emergency room. And, which was, you know, that was kind of upsetting to see... When the people from the home were there, from the assisted living care facility, when they were there, everything was fine. But the minute somebody was not there in the room with him, then the care very definitely was less acceptable."*
>
> *-daughter of a man in his 80s with cancer*[4]

Sadly, too often older persons in nursing homes and their family are "lost in transitions" 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 rate of health care transitions that frail older persons experience and the implications of living in a geographic region with a higher rate of transitions. For frail older persons residing in a nursing home, rates of transitions in the last six months of life vary from a low in 1.9 per person (Salem, OR) to a high of 5.1 transitions per person (Monroe, LA). Such transitions are costly, can often be avoided, and lead to interventions that many would classify as futile. For example, the literature is unambiguous in documenting that feeding tubes for people with end stage dementia do not improve survival, prevent aspiration pneumonia, or help in healing of pressure sores. Yet persons living in a region with high rates of health care transitions are 2.5 times more likely to have a feeding tube inserted than persons in other regions.

We can improve

One in seven nursing home residents have persistent severe pain.[5] Yet, a study conducted in RI nursing homes and replicated across the nation has demonstrated that we can improve the treatment of pain in the nursing home setting. In a demonstration project done in partnership with the state of Rhode Island, the local quality improvement organization, and Brown University, a multifaceted intervention achieved a 41% reduction in severe pain among residents in participating nursing homes.[6] This effort would not have been possible without the support of the Attorney General's Task Force on End of Life Care created by Senator Whitehouse, then the Attorney General of Rhode Island.

Research clearly shows that hospice improves the quality of pain management, improves satisfaction, and helps to prevent terminal hospitalizations of dying persons. One study that found a 47% reduction in rate of terminal hospitalizations.[7] Hospice teams care for people in their own homes and in special inpatient hospice units. Additionally, a multidisciplinary hospice team provides care for people when their "home" is a nursing home. Hospice is one of the few segments of our health care system that exemplifies patient and family centered care. For those dying in nursing homes, the multidisciplinary hospice team provides hope for a tolerable death not marred by pain or other symptoms, assures emotional support, and treats the older dying American with dignity and respect. Time and time again, I have heard family members state, "I no longer had to fight for the right care. I could just be a daughter grieving for my dying mother." The current efforts to cut $2.2

billion from hospice reimbursement over five years will reduce access to hospice, negatively impact the quality of hospice care, and potentially lead to higher health care costs. A 2007 Duke University study[8] found that hospice saves Medicare an average of $2,300 per patient amounting to a $2 billion per year saving for Medicare..

There are solutions

First, a key step to decreasing the rate of costly, burdensome health care transitions are efforts to promote advance care planning, including the completion of advance directives. The creation of an advance directive must be clearly linked to a care plan on how a dying persons wishes will be respected.[9-11] Hospice is a crucial element of that care plan. Hospice allows patients wishes to be honored, ensures adequate palliation of symptoms, prevents inappropriate hospitalizations, and provides the appropriate emotional support of the patient and family.

Second, Congress should assure that there are sufficient number of physicians with the needed training and skills in hospice and palliative medicine to meet the growing needs of the aging population.:

- To promote the growth of the new specialty of Hospice and Palliative Medicine, Congress should exempt palliative medicine fellowship slots from the Medicare GME cap on graduate medical education and should treat palliative medicine fellowships as a primary specialty (akin to geriatrics) as opposed to a subspecialty.

- To develop enough faculty to train the next generation, Congress should fund a Palliative Medicine Career Award akin to the successful GACA program established in 1998.

Third, Congress should pass legislation that provides incentives to reduce the number of burdensome health care transitions and instructs CMS to formulate regulations that holds acute care hospitals and nursing homes accountable for poor health care transitions. Gone are the days when a physician should be able to state "out of my hospital, no longer my responsibility." Hospitals and nursing homes must partner together to decrease inappropriate health care transitions in the last months of life. Promoting advance care planning is the key first step. The approach to prevent these costly poor health care transitions will require changes to the financial incentives, public reporting of quality indicators about poor health care transitions, and regulatory scrutiny. For example, the ongoing intervention of Sacramento hospitals working with local nursing homes to promote advance care planning is one such partnership that other regions of the country might consider adopting. The bottom line is that hospitals must be accountable for what happens to older, frail persons when they leave their doors. They must be the leaders in improving the quality of care for their community.

Fourth, the current Center for Medicare and Medicaid Services ruling that will cut hospice reimbursement should be rescinded. I urge support of the Medicare Hospice Protection Act (H.R., 6873 and S 3484).. Furthermore, I would recommend expanding the role of hospice in nursing homes. The Medicare Hospice Benefit was designed around the needs of persons dying of cancer. Increasing, dementia is a leading cause of death in the USA. These people need the same access to high quality palliative care in their final stages of life. Among those persons with dementia who are enrolled in Hospice, many are enrolled in the last days of life because of the current perverse incentives to provide skilled rehabilitative services. Congress needs to realign these incentives that keep persons "skilled" while dying in a nursing home. This current set of incentives contribute to multiple costly, hospitalizations and hospice referral only in the last days of life. This expansion should be done in a manner that guarantees high quality care through appropriate regulatory oversight and public reporting of hospice quality.

So what are the lessons learned from Oscar the nursing home cat who holds vigils with dying persons? Does Rhode Island have a psychic cat? My answer is no—rather we have an exemplary nursing home that partners with Home and Hospice Care of RI to provide high quality care. Oscar is just mimicking the staff's loving care. As one elderly women wrote to us in an e-mail, she hoped that she would die in a nursing home with a cat on her bed. Our hope is that policy makers will recognize the importance of adequate funding so a hospice nurse, social worker, spiritual counselor, and volunteers can be at that patient's bedside. We must adequately fund and demand high quality of care for frail, older Americans whose last home is a nursing home.

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

References

1. Dosa DM. A day in the life of Oscar the cat. *N Engl J Med.* Jul 26 2007;357(4):328-329.
2. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. *J Am Geriatr Soc.* Feb 2005;53(2):299-305.
3. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA.* Jan 7 2004;291(1):88-93.
4. Wetle T, Shield R, Teno J, Miller SC, Welch L. Family perspectives on end-of-life care experiences in nursing homes. *Gerontologist.* Oct 2005;45(5):642-650.
5. Teno JM, Weitzen S, Wetle T, Mor V. Persistent pain in nursing home residents. *JAMA.* Apr 25 2001;285(16):2081.
6. Baier RR, Gifford DR, Patry G, et al. Ameliorating pain in nursing homes: a collaborative quality-improvement project. *J Am Geriatr Soc.* Dec 2004;52(12):1988-1995.

Joan M Teno, M.D., M.S. Testimony for the Senate Special Committee on Aging
September 24, 2008

7. Gozalo PL, Miller SC. Hospice enrollment and evaluation of its causal effect on hospitalization of dying nursing home patients. *Health Serv Res.* Apr 2007;42(2):587-610.
8. Taylor DH, Jr., Ostermann J, Van Houtven CH, Tulsky JA, Steinhauser K. What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program? *Soc Sci Med.* Oct 2007;65(7):1466-1478.
9. Teno JM. Advance directives: time to move on. *Ann Intern Med.* Jul 20 2004;141(2):159-160.
10. Teno JM. Advance directives for nursing home residents: achieving compassionate, competent, cost-effective care. *JAMA.* Mar 15 2000;283(11):1481-1482.
11. Teno JM. Looking beyond the "form" to complex interventions needed to improve end-of-life care. *J Am Geriatr Soc.* Sep 1998;46(9):1170-1171.

Senator WHITEHOUSE. Thank you, Dr. Teno. It's now my honor and privilege to call on Attorney General Drew Edmondson.

STATEMENT OF W.A. DREW EDMONDSON, OKLAHOMA ATTORNEY GENERAL, OKLAHOMA CITY, OK

Mr. EDMONDSON. Thank you, Senator Whitehouse, Chairman Kohl, members of the Committee. I'm honored to be asked to be here today, particularly honored to be with two of my former colleagues, who after accomplishing great things in the Office of Attorney General had the good sense to move on. I will try to remember that the prerogative of unlimited debate on the Senate side rests with the Senators and not with the witnesses.

We are here talking about an issue that we tend to think in terms of an issue belonging to the elderly. I would simply remind in passing that two of the highest profile cases we have had, the Terry Schiavo case and the Nancy Cruzan case involved people in their 20's and that when we talk about advance directives and conversations, we need to be having these conversations with our children as well as with our parents. So that was a point that I wanted to make in passing.

I got involved in this issue because of a meeting that I attended with my wife, who is a medical social worker. It was her meeting. I was there as the spouse. The speaker was Myra Christopher, who at that time was Executive Director of the Midwest Bioethics Center which is now the Center for Practical Bioethics.

Myra Christopher, addressing the audience said, if I were to ask you what you envisioned and hoped for in your end of life, some 80 percent of you if you track national polls, would say that you would prefer to die at home, free from pain and in the company of family and friends. Myra went on to say, you can turn that statistic on its head because in fact, some 80 percent of you will die in a hospital or nursing facility, you will die in pain that could be managed and is not being managed and you will die isolated from family and friends. It was not my meeting, but I was sitting there as Attorney General saying, what's wrong with this picture?

Every person in the State of Oklahoma is a consumer of healthcare and they were all constituents of mine. If there are barriers between what people want in their end of life situation and what they're actually receiving in the real world, I need to find out what those barriers are and what we can do to eliminate them. So we had the conference, the listening conferences on end of life care around the nation, in Kansas City, in Baltimore, and in San Diego.

We asked three questions from a consumer standpoint. Will my wishes be known and honored? Will I receive adequate pain management? Will I receive competent care?

We assembled panels of experts. We assembled people who had gone through this experience with loved ones. The stories that we heard were shocking and frightening about advanced directives that were not followed, people who were in pain that could be managed and were not treated across the country and the call to action was unmistakable.

That call has been answered in many states and by the Federal Government in many ways at conferences, task forces, initiatives in state after state. So I commend you for continuing that effort to answer those questions and provide a better situation for people who are facing those situations. I would offer two things that you might consider in doing that.

First, physicians deserve adequate medical care reimbursement for the time they take to discuss end of life decisions and advanced care planning with their patients. The counseling that physicians provide about advance directives is as important as any test or procedure that they might provide.

Second, the six month terminal diagnosis that is required for the Medicare Hospice Benefit should be more permeable allowing terminally ill hospice patients access to palliative treatment, not currently allowed. There should not be an artificial division between ordinary medical care and hospice care.

I hope that the things that have been done by Attorneys General have been helpful in reaching these goals and answering those questions. I am very hopeful that the work that you're engaged in: the work that you're talking about doing, the work that will go forward by this Committee and the Congress of the United States will do that as well.

We were told during our conferences by an Assistant Attorney General named Jack Schwartz from the State of Maryland that if at the end of our terms that we could say that as a result of our work, we had lessened the level of human suffering in our states. Than no matter what else we do, we could count our service to be well done. I offer that same commendation to you. Thank you very much.

[The prepared statement of Mr. Edmondson follows:]

Testimony

of

W.A. Drew Edmondson

Oklahoma Attorney General

Before the

US Senate Special Committee on Aging

September 24, 2008

It has been said that only two things in life are certain; I am here today to discuss one of the two.

Whether it is our own death, or that of a close friend or family member, each of us will in all likelihood eventually be faced with the agonizing decisions that impending death brings. When that moment arrives, I wonder how many of us have thought about the choices we would make for our own care and comfort at the end of life. What kind of medical treatment do we want? What don't we want? How many of us have taken the time to put those choices in a legal document, so that when the time arrives, our families are not faced with decisions about things like breathing machines and tube feeding?

The truth is that when asked about the ideal picture of what our own deaths will look like, most of us share the same vision: to be free of pain, to be at home surrounded by family and friends and to have our wishes known and honored. Unfortunately, in Oklahoma and across the country, the opposite is occurring all too often. Most of us will die in a health care facility, pain that could be controlled and is not, and we are isolated from loved ones. As a health care consumer, and as an attorney general responsible for consumer protection, it troubles me greatly to think that for most of us, our last moments on earth will not meet that ideal standard. There simply must be a better way.

Recognizing that fact, I chose end-of-life health care as a presidential initiative during my term as President of the National Association of Attorneys General from 2002-2003. The cornerstone of the initiative centered on three regional listening conferences that provided an opportunity for attorneys general to hear compelling stories recounted by the mothers, brothers, children and spouses who were thwarted in efforts to fulfill the wishes of dying loved ones.

We challenged national experts to testify before assembled panels of attorneys general and to address the three questions repeatedly raised by consumers: "Will my pain be managed?" "Will my wishes be known and honored?" and "Will I receive competent care?"

These clinicians and health care advocates reported that some state legislatures and professional licensing boards are beginning to adopt policies to encourage better pain management, to clarify the role of opioid analgesics and to address physicians' fears of being investigated for inappropriate prescribing of controlled substances. We also heard that there was a significant gap between policy and practice.

We heard from physicians and nurses who cited deficits in educational requirements in medical, nursing, social work and pharmacy schools for end-of-life health care. As consumers, we expect these professionals to be trained in pain management and be informed regarding health care choices, such as hospice. To the contrary, statistical studies reflect a lack of education as a major factor contributing to substandard care near the end of life. Doctors are trained to save life – to find cures, to restore health. To many of them, the death of a patient is a failure rather than an inevitable fact of nature. Some do not, therefore, study or prepare for their role in caring for the dying.

As attorneys general, we learned about the barriers that exist between the typical and the desired care as we are dying. These are barriers that must be removed if we are to improve end of life care.

Armed with the information we learned on the national level, I and some other attorneys general took what we had learned back home and worked to make improvements in the areas discussed and studied. These actions have been overwhelmingly popular with citizens in states including Arizona, Maine, Missouri, Oregon and Vermont.

In Oklahoma, I formed a state task force made up of 15 Oklahoma legal and health care professionals. In addition to the members of the task force, more than 70 members of an advisory committee worked to identify the existing legal, policy and educational barriers to quality end-of-life care in Oklahoma. This group heard from experts in areas of concern including advance directives, nursing facilities, hospitals, hospices, care for children and other issues.

Then the task force issued a series of recommendations to improve end-of-life care. Their work focused on changes that could be made in Oklahoma, and their continued work has led to the implementation of many of the task force recommendations.

In 2006, we worked to pass Oklahoma Senate Bill 1624, which improved the statutory advance directive form and acknowledged a patient's unlimited right to accept or refuse life-sustaining treatment.

Also, the bill remedied an unconstitutional portion of Oklahoma law that limited a patient's right to accept or refuse care to instances of illnesses diagnosed as terminal within six months or those patients deemed to be in a persistent vegetative state. The earlier law did not allow for patients whose terminal diagnosis exceeded the six-month time frame.

Additionally, Oklahoma is working to remove some of the educational barriers that persist. The Oklahoma Palliative Care Resource Center now provides training for doctors and nurses on palliative care, specifically focusing on pain management and other symptoms when a cure is no longer possible. The task force has created a written guide for health care professionals and citizens that contains guidance regarding Oklahoma's Advance Directive and other advance care planning information.

On another front, state attorneys general have also been working with the DEA on policies that will allow law enforcement to prosecute the diversion of prescription drugs without curbing doctors' abilities to prescribe pain killers to patients who suffer from constant pain. This is an important policy shift that we hope will ease the perception among doctors that prescribing painkillers will automatically draw the attention of prosecutors. I would seek your attention to this effort with the DEA for a balanced pain policy – pursuing wrong-doers while supporting physicians who are seeking to provide adequate pain management.

I would also draw your attention to two other areas where federal action could improve end-of-life care. First, physicians deserve adequate Medicare reimbursement for the time they take to discuss end-of-life decisions and advance care planning with their patients. The counseling that physicians provide about advance directives is as important as any test or procedure they might provide.

Second, the six-month terminal diagnosis that is required for the Medicare hospice benefit could be more permeable, allowing terminally ill hospice patients access to palliative treatments not currently allowed. There should not be an artificial division between ordinary medical care and hospice care.

I hope that the things I have done as attorney general create a better picture for everyone who will, one day, die in Oklahoma. By easing uncertainty among health care professionals and their patients, I believe our state is better equipped to meet the needs of its citizens.

While we are proud of the work that has been done, we recognize that there is much still to do. The right to choose our own courses of treatment as we near the end of life is one that should be honored and upheld at the highest level.

You are in a unique position to improve the life and death, of each and every American. As a public servant, I can think of no finer legacy than to reduce human suffering in this country. As a citizen and health care consumer, I offer my deepest gratitude for your efforts.

Senator WHITEHOUSE. Thank you Attorney General Edmondson. Our final witness is Dr. Bomba.

STATEMENT OF DR. PATRICIA BOMBA, VICE PRESIDENT AND MEDICAL DIRECTOR, GERIATRICS, EXCELLUS BLUECROSS BLUESHIELD, ROCHESTER, NY

Dr. BOMBA. Senator Whitehouse, Chairman Kohl, members of the Committee, thank you for the opportunity to provide testimony today. It's not about me. It's not about you. It's really, truly about the people we serve.

I've had an interest in end of life care, personally and professionally since 1983. It's poignant that I'm here today as our family has suffered four losses in the past 9 months with four elders age 75 to 95, including my mother, maternal and paternal uncle and my maternal aunt. My uncle is being buried today.

I would like to end with some positive stories that reflect advance care planning can have a positive outcome. The variation in terms of where palliative care and hospice has provided can be across the board. My paternal uncle died acutely and received intensive palliative care in an intensive care unit. My second uncle who was just transferred and died this past week was able to be transferred from an intensive care unit into a free standing hospice unit and died peacefully. My mother was able to die in our home after 3 months of hospice care. They all received intensive palliative care services. Their stories were different.

What they had in common was that the conversation that we had not only with their providers, but within our family made the difference. Even as an expert, at the end, we have our emotions and you're still losing a mom. My expertise came from an 85 year old woman who in 1983 challenged me to say, you don't feel comfortable talking about death and you must because it's about my death, not your death. She taught me how important it was to be able to provide accurate prognostication so that her end of life and her final chapter could be hers.

The importance of informed medical decisionmaking and not just asking would you like this intervention or not and to have it based on goals for care. Being sure the patient is able to understand if the treatment would make a difference, understand the benefits and burdens, and if is there is hope of recovery, what would life be like afterwards? Most importantly what do I value focussing on the importance of patient centered care in separating out personal wishes verses the professional's.

Eight years ago I assumed a position in a not-for-profit health plan. In the role I represent not only myself or the health plan, but frankly I'm the leader of a community wide, end of life palliative care initiative. So I here represent countless individuals, healthcare professionals, professional associations and consumers.

Before I talk about the two major advance care planning initiatives, I want to share about the initiative. We started in Rochester, NY with more than 150 community volunteers, a broad perspective of healthcare professionals from hospitals, from nursing homes, disease management programs. We included consumers.

We have a broad coalition with diversity from both a spiritual and cultural perspective. We have leadership that included consumers. We focused in four major areas.

We want to increase the completion rate of advance directives. We want to assure that once those were honored that we would assure that preferences were honored once the directives were there. We want good pain and symptom management. We want to focus on education and communication.

We've developed programs that I'll speak of today. One is the Community Conversations on Compassionate Care, a program to encourage all individuals 18 and older, to do traditional advance directives. In our state, a healthcare proxy, in other states a durable power of attorney for health care. Focusing on two important concepts, who is the right healthcare agent, not necessarily the daughter, the son, but who is the right person who can act on behalf of the individual? Second, what are the values, beliefs of the individual?

We've encouraged that for everyone including young people. As our colleague Attorney General Drew Edmondson said, it's not just for the serious ill, but we need to think about young people as well. We ask people to have value statements.

My son, who is currently a 25 year old law student's value statement was, "without my mind, pull the plug. It's my time. If I have the ability to think, to feel, to speak then yeah, I'll stay." The concept was personhood, but it wasn't merely written on a document. It was shared in a family discussion around the kitchen table. We call them healthcare proxy parties. So we encourage that type of discussion.

We also had a second group called MOLST. We developed the Medical Orders for Life Saving Treatment Program, which is New York State's version of the POLST Paradigm program that you've heard spoken of earlier. We focused on community principles of pain management. We have developed a community website.

We began with data. We started with the community survey after the Institute of Medicine said we could do better nationally. What we found looked at advance directive rates hospice referrals and pain management.

Less than 20 percent of our patients in home care services had advance directives at that time without regard for whether they had cancer, heart disease, lung disease or dementia. We knew we could do better.

Senator WHITEHOUSE. If you could sum up when you have a chance, Dr. Bomba.

Dr. BOMBA. What's that?

Senator WHITEHOUSE. We're beyond time. If you could sum up?

Dr. BOMBA. Oh, ok. The program on community conversations includes five easy steps to get people to be motivated to complete directives. The MOLST program was put together based on national research.

We were able to find the POLST program and we adapted it for New York State. We've been able to change what we weren't able to have in our state currently which was EMS was not allowed to follow any form but a simple form. They were not allowed to follow do not intubate orders.

We've changed the scope of practice. Governor Patterson signed the MOLST into law in July of this year. We have had training across the country.

What I would ask the Committee to consider is to look at the POLST Paradigm as a national model. That has been recommended before. I would also suggest looking at the national quality forum, five platforms for advanced care planning. Assuring a system wide approach to knowing who surrogate decisionmakers are.

Second, to understand values at every site of care.

Third, for the right group, those with a prognosis with seriously ill individuals a prognosis of less than a year, covert the orders—convert the wishes, rather, into actionable medical orders with a promise by healthcare professionals to follow those orders because Oregon has found that that works.

The next is to assure accessibility and to do community education programs.

I would concur with Attorney General Edmondson in terms of funding with one caveat. We need to align incentives for the conversation. We need to incentivize action. We need to be able to look at Medicare currently and recognize that we can't just do face to face conversations.We need to be able to acknowledge conversations with healthcare agents. As well as guardians.

Senator WHITEHOUSE. Thank you very much.

[The prepared statement of Dr. Bomba follows:]

Compassion and Support
at the End of Life
www.CompassionandSupport.org

MOLST
MEDICAL ORDERS FOR
LIFE-SUSTAINING TREATMENT

Senate Special Committee on Aging

Senator Sheldon Whitehouse, Chair

"Honoring Final Wishes: How to Respect Americans' Choices at the End of Life"

September 24, 2008

10:30 a.m.

Dirksen Senate Office Building, Room 562

Testimony

Patricia A. Bomba, M.D., F.A.C.P.
Vice President & Medical Director, Geriatrics
Excellus BlueCross BlueShield
Leader, Community-Wide End-of-life/Palliative Care Initiative
Chair, Monroe & Onondaga Counties Medical Orders for Life-Sustaining Treatment (MOLST)
Community Implementation Team and New York Statewide Implementation Team
New York State Representative, National Physician Orders for Life-Sustaining Treatment (POLST) Task Force

POLST

MOLST

Good morning. I extend my thanks to Senator Sheldon Whitehouse and members of the Senate Special Committee on Aging for convening this hearing on "Honoring Final Wishes: How to Respect Americans' Choices at the End of Life" and affording me the opportunity to provide testimony process from both a personal and professional perspective.

Too often, people don't die in the setting of their choice, don't have advance directives in place, and many fear dying in pain and without dignity or control. We can – and must, do better.

I have been personally committed to ensuring the rights of all Americans to receive high quality, person-centered care since 1983 when an 85 year old female patient taught me the importance of:

- comfortably discussing death and dying,
- sharing prognostication that allows an individual sufficient time to close one's life,
- participating actively in the advance care planning process and ensuring informed medical decision-making so that patients and families recognize whether a treatment is necessary; the benefits and burdens of that treatment; if there is hope for recovery and if so, what life will be like afterwards; and most importantly, exploring what the patient values,
- person-centered care – she taught me, "It is my life and my death, not yours."
- separating my beliefs from a patient's beliefs.

She gently reminded me why I originally choose medicine as a career. At an early age, I witnessed the negative impact of ineffective end-of-life care of my maternal grandmother and several other relatives on the health of family members for many subsequent years. My father died suddenly three weeks before I graduated from medical school in 1979 and medical school trained me to save lives – not care for the dying.

In the past nine months, my family and I have experienced the loss of four significant elder family members, namely, my mother, paternal aunt, paternal uncle and maternal uncle. I was engaged in the advance care planning process and ensuring my mother and two unmarried uncles' final wishes were honored and that they received effective end-of-life care. I was unable to be directly involved in my aunt's care as she died two weeks before my mother. Their final wishes were openly discussed with our family long before their illnesses and death.

- I was privileged to care for my mother during the last 15 months of her life. She died in our home after receiving in-home hospice care for nearly three months subsequent to being diagnosed with a serious illness when she was hospitalized with acute abdominal pain, while visiting my sister in another state. Her Medical Orders for Life-Sustaining Treatment (MOLST) form traveled with her and the medical orders were honored.
- My paternal uncle died after a cascade of medical events subsequent to a fall experienced two weeks after my mother's death. While on the apparent road to recovery, he sustained an acute event associated with multisystem organ failure. He was treated with aggressive palliative care measures and died peacefully in an ICU in less than 24 hours after admission and appropriate assessment.
- My maternal uncle, the last remaining sibling of my mother and our family's surrogate father, died peacefully on September 17th in a free-standing inpatient Hospice Home, four days after admission. Significantly, he was admitted to an ICU nine days prior to his death and was able to be transferred from the ICU to the Hospice Home in less than 48 hours after the need for effective palliative care was recognized. He had no prior hospitalizations during the antecedent two years.
- Each of my relatives accepted and embraced a natural death and recognized the limitations and burdens of life-sustaining treatment. While the scenarios and clinical settings varied, each received appropriate aggressive palliative treatment and experienced a peaceful natural death.

As a geriatrician with 30 years of clinical experience in private practice, long term care and academic settings, I recognize failure to provide compassion and support at the end-of-life results in unnecessary suffering for the patient and family and poor quality of life for the patient.

Now as a medical director of a not-for-profit health plan, my work focuses on spearheading development, implementation and statewide expansion of

- community projects that focus on advance care planning, pain management, palliative care, end-of-life care, and elder abuse
- professional and community educational interventions that aim to overcome functional health illiteracy, and
- integration of these programs into our care management functions and products.

I am privileged to lead the ***Community-wide End-of-life/Palliative Care Initiative (Initiative)*** that focuses on a systems approach to advance care planning, pain management, palliative care and end-of-life care. Formed in 2001, members of the Initiative first examined the social, legal and institutional barriers to higher rates of advance directives and health care proxy documentation. The Initiative sought a patient-centered, system-based, community-wide solution to improving both completion rates of traditional advance directives and provider compliance that would ensure patient preferences would be honored across the continuum of care. View information on the Initiative and Initiative outcomes at the community web site, www.CompassionandSupport.org.

While the Initiative has several projects including Community Principles of Pain Management, palliative care programs, palliative medicine workforce development, PEG Tube Feeding Guidelines, professional and consumer educational interventions, I will focus my testimony on goals and outcomes of two complementary advance care planning programs developed by the Initiative that enhance the potential for improving patient-centered care:

- ***Community Conversations on Compassionate Care (CCCC)***, an advance care planning program designed to motivate all adults 18 years of age and older to complete traditional advance directives like the health care proxy and living will.

- *Medical Orders for Life-Sustaining Treatment (MOLST) Program*, New York State's approved *Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program*, designed to improve the quality of care seriously ill people receive at the end of life by "Writing Your Final Chapter: Know Your Choices...Share Your Wishes."

Community-wide End-of-life/Palliative Care Initiative (Initiative)
Background on Regional Efforts to Improve End-of-life Care in Upstate New York

To understand these two advance care planning programs, it is important to recognize the

- Initiative's health care and community collaborative model
- context in which the Initiative initially developed local efforts to improve end-of-life care in Upstate New York
- strategy used for regional implementation, and
- steps taken to move the projects statewide and nationally.

Subsequent to the publication of the 1997 Institute of Medicine Report "Approaching Death: Improving Care at the End-of-Life", the Rochester Individual Practice Association and BlueCross BlueShield Rochester Region End-of-Life/Palliative Care Professional Advisory Committee was formed. This Committee developed and implemented the Rochester Community End-of-Life

Survey focused on advance directive completion rates, effective pain management and hospice referrals conducted in October – November 2000. Survey results revealed there was significant room for improvement in end-of-life care.

Results were presented to the Rochester Health Care Forum in January 2001 and the Community-Wide End-of-Life/Palliative Care Initiative was launched in May 2001. Initially, more than 150 passionate community volunteers participated in launching the Initiative and the development of projects showcased on the community Web site, www.CompassionandSupport.org. Initiative leadership and membership includes a broad diverse representation of the community, including consumers. Partnerships with spiritual, religious and cultural organizations ensure the interventions are culturally sensitive. As the initiative began, leadership and the Advisory Group felt strongly that a focus should be placed on the development of projects that support the vision. "Rochester will be a preeminent leader in advocating for facilitated discussions on planning for end-of-life care and for ensuring excellence in the provision of End-of-Life/Palliative Care, serving all segments of our community." Details are outlined in A Report to the Community.

To assist the Advisory Group and gather community input, four workgroups were formed:

- Workgroup 1 Exploring and communicating treatment wishes
- Workgroup 2 Ensuring patient wishes are identified and honored at all sites of care
- Workgroup 3 Relieving physical, psychological, spiritual symptoms and providing patient/family support
- Workgroup 4 Facilitating communication and education, both community and professional.

Leadership and administrative support is provided by Excellus BlueCross BlueShield, including funding for operations, creative services, communication, distribution and fulfillment of educational materials, training, and quality improvement. Staff assists in monitoring performance, sharing best practices and lessons learned and establishing plans for sustainability.

The initiative has grown with countless individuals working on replicating Initiative projects across New York State. The EPEC faculty from across Upstate New York share our mission of providing high quality, person-centered, effective care at the end-of-life and play a critical role in collaborating on concrete projects and replicating our efforts in Upstate New York. Professionals and community volunteers from Western New York, Central New York, Utica Region, Southern Tier and the North Country participate in the development and implementation of these projects; for example, the Southern Tier End-of-Life Coalition, a coalition concerned with improving end-of-life care in the greater Binghamton area and the Community Health Foundation, a non-profit organization providing funding to seven Central and Western New York coalitions aiming to improve care for frail elders.

The Community-wide End-of-Life/Palliative Care Initiative collaborates with multiple stakeholders for its various projects, including national, state, regional and local organizations; hospital, long term care, EMS, home care, palliative care and hospice systems; physician and legal professional associations; academic institutions and quality improvement organizations; religious organizations and cultural groups; community agencies, business organizations and other insurers. View a full list of collaborators.

Before initially developing strategy and plans, the Initiative examined the scope of the problem, researched existing models and outlined the needs assessment for traditional directives for all Americans and the need for "actionable medical orders" for seriously ill patients. The interventions developed were a direct result of these individual needs assessment.

Needs Assessment for Traditional Advance Directives for All Individuals

Workgroup 1 Exploring and communicating treatment wishes

Any individual can face sudden, unexpected life-limiting illness or injury. Advance care planning is a process of planning for future medical care preferences if one loses decisional capacity and for preparing for death. Thus, advance care planning is appropriate for all adults 18 years of age and older, not only the subset of Americans with life-limiting illness. The process addresses surrogate decision-making and end-of-life preferences and focuses on conversation among the patient, their family, physician and other health care providers, clarification of values and beliefs and choice of a trusted surrogate to represent them when they can no longer speak for themselves. The result is completion of accessible legal documents and a commitment to periodic reassessment and update.

Absence of legal documents can result in situations illustrated by Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo.

The advance directive completion rate in our nation has not significantly increased since the passage of the Patient Self-Determination Act in 1991. Means to a Better End, the first national report card on end-of-life care, revealed only 15-20% of Americans has some form of advance directive[i]. It is likely that even fewer have had the open, honest conversations regarding end-of-life care wishes, the other vital component to the Advance Care Planning process.

More recently, a nationwide poll conducted by the AARP Bulletin in 2007 found that more than 90% of adults 35 or older are aware of Health Care Proxies and Living Wills, but less than 40% have actually completed these forms.[ii] Similarly, a nationwide poll conducted by the Pew Research Center in 2005 found that 95% of adults had awareness but only 29% of Americans had completed an advance directive, specifically a living will; Health Care Proxy completion rates were not addressed.[iii]

Community Conversations on Compassionate Care (CCCC) Program:

Workgroup 1 Intervention - Traditional Advance Directives for All Individuals

The *Community Conversations on Compassionate Care (CCCC)* Program aims to promote conversations and actions that motivate all persons 18 years of age and older, including healthy individuals to complete traditional advance directives, not only the subset of Americans with life-limiting illness.

The CCCC Program combines storytelling with Five Easy Steps for completing an advance directive integrating Prochaska's behavioral readiness theory:

1. Learn about Advance Directives
2. Remove barriers
3. Motivate yourself
4. Complete the Health Care Proxy form
    a. Have a conversation with your family
    b. Choose the right Health Care Agent
    c. Discuss what is important to you.
    d. Understand life-sustaining treatment
    e. Share copies of your directives
5. Review and update

The program features consistent messaging on Advance Care Planning and community resources including an advance care planning booklet, an interactive workshop, video, online resources at www.compassionandsupport.org and internal tracking and evaluation.

In addition, the CCCC Program has been integrated into care management functions as well as the new product, Healthy Blue and developed internally as a Worksite Wellness Program.

CCCC Program History:
The Initiative launched the Advance Care Planning program with a press conference in Rochester in September 2002 press conference that featured David Klein, CEO and President, Dr. Patricia A. Bomba, Vice President and Medical Director, Geriatrics, ten spiritual leaders and community members. The spiritual leaders, including Catholic, Episcopal, Jewish, and Muslim leaders, ceremonially signed their advance directives during the press conference. The spiritual leaders vouched for the role Advance Care Planning plays in end-of-life care and confirmed Advance Care Planning is consistent with the teachings of their respective faith. The community members discussed how Advance Care Planning helped alleviate the stress and burden associated with the death of a loved one. Excellus BCBS copies this format for Advance Care Planning programs launched in other regions. View Press Conference with Spiritual Leaders.

Studies have demonstrated that physician counseling markedly increases the completion rate of advance directives.[iv,v,vi,vii,viii,ix,x] To be effective, counseling should include key elements of the advance care planning process and be individualized according to the patient's current condition and behavioral readiness to complete an advance directive.[xi] Given physician-reported barriers of time and unwillingness to press discussions with patients, further research on effective interventions[xii,xiii] is needed.

From the patient perspective, advance care planning is not based solely on autonomy and the exercise of control, but also on personal relationships and relieving burdens placed on others. Advance care planning is a gift to self and family that decreases turmoil and suffering at the end-of-life, thus easing the burden for families of persons with life-limiting illness. By recognizing that advance care planning does not occur solely within the context of the physician-patient relationship, counseling should include advising conversations within the patient/family unit and within relationships with close loved ones. An integrative approach to advance care planning can be provided by physician, nurse, social worker, and/or patient advocate in the primary care setting.[xiv]

Tools and Resources:
The Advance Care Planning booklet is divided into five main sections:

1. Clarifying values and beliefs
2. Choosing an appropriate Spokesperson
3. Discussing your values, beliefs, wishes and goals of care with loved ones, your Spokesperson and physician
4. Documenting your wishes using the appropriate legal forms
5. Practical issues related to Advance Care Planning including accessibility and reviewing and updating as needed

The booklet, available in English and Spanish, is distributed free of charge by Excellus BlueCross BlueShield and is available in the advance care planning section of the Resource Directory.

An interactive Advance Care Planning workshop called *Community Conversations on Compassionate Care* (CCCC). CCCC is a free one-and-a-half hour workshop designed to increase comfort with discussing death and dying through storytelling and improve community members' involvement in Advance Care Planning. The focus on storytelling is designed to engage the consumer in the conversation and motivate the behavioral change needed to participate in the Advance Care Planning program. Each attendee receives a folder of material containing the Advance Care Planning booklet, a handout of the PowerPoint presentation and a two-page outline covering the vital aspects of Advance Care Planning. View *Community Conversations on Compassionate Care* (CCCC).

To expand educational efforts on traditional advance directives, the *Community Conversations on Compassionate Care* (CCCC) video was produced. It is based on the CCCC workshop. The CCCC video is a video that aims to motivate healthy individuals to complete traditional advance directives. The program uniquely combines a storytelling approach with "Five Easy Steps" based on Prochaska's behavioral readiness theory and has been recognized by the National Quality Forum. It can now be viewed on-line at www.CompassionandSupport.org. Go to the callout area labeled CCCC video preview at the bottom of the home page of www.CompassionandSupport.org to view a 2 minute excerpt. View the entire CCCC video along with the Five Easy Steps here.

Training of Health Care Professionals:

To extend the reach of the CCCC workshop throughout Upstate New York, Excellus BCBS developed a Facilitator Training Workshop. The Facilitator Training Workshop is a full-day training session that provides the attendees with the tools needed to facilitate the workshop. This training is also ideal for individuals that deal with Advance Care Planning on a daily basis or perform one-on-one Advance Care Planning education. Topics covered in the Facilitator Training Workshop include Facilitator Skills, Workshop Logistics, Advance Care Planning along the Health-Illness Continuum, the Patient Voice in End-of-Life Transitions, Life-Sustaining Treatments and Medical Orders for Life-Sustaining Treatments (MOLST).

Each Facilitator Training Workshop attendee receives a comprehensive binder of information including the aforementioned topics, plus CCCC workshop information and facilitator supporting information. A CD-ROM, featuring the binder information in PDF format and CCCC PowerPoint presentation, is also included in the binder.

Excellus BCBS successfully trained numerous local partners to offer the CCCC workshop to the community and to facilitate discussions on Advance Care Planning on a one-on-one basis. Excellus BCBS supports the partners by supplying workshop folders and booklets. Excellus BCBS also collects post-workshop data and analyzes pre- and post-workshop data for the partners.

Pertinent resources on Advance Care Planning are available in the Web site's section for Professionals, the Resource Directory, and the References section.

- Community Conversations on Compassionate Care (CCCC) Video
- Advance Care Planning Clinical Pathways
    - Life Expectancy >1 Year
    - Life Expectancy <1 Year

Training for Patients/Families/Community:

The CompassionandSupport Web site is a community Web site dedicated to educating and empowering patients, families and professionals on advance care planning, MOLST, palliative care, pain management and hospice care and related topics. The Web site was developed in 2001 to overcome functional health illiteracy, and was enhanced in 2007. View the Patients & Families section of the Web site.

Pertinent resources on Advance Care Planning are available in the Resource Directory, along with an array of resources on related topics.

CCCC Program Outcomes Evaluation – Upstate New York Community Survey Results:

The CCCC Program's success is validated by the End-of-Life Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions, Summary Report, 2008.

To assess consumer attitudes and actions regarding two important advance directives (Health Care Proxies and Living Wills), Excellus BlueCross BlueShield commissioned United Marketing Research to conduct interviews with a random sample of residents living in a 39-county area of upstate New York. Between March 6, 2008 and April 6, 2008, a total of 2,000 adults, 18 and older, were interviewed by telephone. Respondents were selected at random using a random digit dialing (RDD) sample. A quota sampling approach also was used to ensure that a meaningful number of individuals (about 400) would be surveyed within each of five regions (Rochester, Central New York, Utica, the Southern Tier and Western New York). Quotas also were established for respondents 55 and older to help minimize age bias associated with telephone surveys. The margin of error for the overall sample (n = 2,000) is approximately ±2.5%; for each region, the margin of error was ±5%.

Specific issues explored on the survey included:

- Awareness and knowledge of Health Care Proxies and Living Wills
- Completion rates for Health Care Proxies and Living Wills
- Attitudes toward Health Care Proxies and Living Wills
- Reasons for not completing a Health Care Proxy form
- Discussions of Health Care Proxies and Living Wills with family and personal doctor

The results from the survey are intended to provide attitudinal and behavioral assessments for two important advance directives and to identify demographic factors that have the most influence on these attitudes and behaviors.

Key findings and conclusions of the survey included:

- A significant disparity exists between attitudes and actions as they relate to two key advance directives (Health Care Proxies and Living Wills). While most adults in upstate New York feel that Health Care Proxies (88%) and Living Wills (80%) are important for them to have, only 42% have designated a Health Care Proxy and just 26% have completed a Living Will.
- Significant regional variations exist in completion rates for Health Care Proxies. The highest rate is in Rochester (47%) and lowest in Utica (35%). Evidence suggests that the difference is driven, in part, by physician communications with patients as the highest rate of discussion with doctors occurred in Rochester (47%) vs. Utica (27%). Studies in the medical literature have demonstrated that physician counseling markedly increases the completion rate of advance directives.[xv] [xvi] [xvii] [xviii] [xix] [xx] [xxi]
- Age is the most important factor affecting completion rates for Health Care Proxies and Living Wills. As people grow older, they are much more likely to engage in advance care

planning, especially after they reach age 65. Other demographic factors that influence the decision to act include gender and level of education.

- Age, gender, and level of education also affect awareness of and attitudes toward advance directives. In general, women and adults age 35 and older are more likely to perceive Health Care Proxies and Living Wills to be important.

CCCC Program Outcomes Evaluation – Serial Employee Healthcare Decisions Survey Results:

The CCCC Program's success is also validated by the serial increase in completion rates among Health Plan employees.

- View the on-line 2008 Employee Healthcare Decisions Survey.
- View the Employee Healthcare Decisions Survey Report, 2008.

An advance care planning employee campaign held in October through November 2007 was initiated by an email message from CEO David Klein followed by a series of emails from Dr. Patricia Bomba, a national expert on advance care planning. Interventions utilized were developed in response to information derived from the 2006 Employee Healthcare Decisions Survey and included educational sessions, web-based information, the *Community Conversations on Compassionate Care* video and financial incentives.

In 2002 and 2006, Excellus BlueCross BlueShield conducted surveys of all its employees to assess their knowledge and actions regarding two key advance directives, Health Care Proxies and Living Wills. During the four-year period extending from 2002-2006, the completion rates for Health Care Proxies rose from 30% to 34% among employees, while completion of Living Wills remained essentially unchanged (18% in 2002 vs. 17% in 2006).[xxii] [xxiii]

Few studies on advance directives have been conducted nationally. A nationwide poll conducted by the *AARP Bulletin* in 2007 found that more than 90% of adults 35 or older are aware of Health Care Proxies and Living Wills, but less than 40% have actually completed these forms (37% reported completing a Health Care Proxy and 36% a Living Will).[xxiv] Similarly, a nationwide poll conducted by the *Pew Research Center* in 2005 found that 95% of adults had awareness but only 29% of Americans had completed an advance directive, specifically a living will; Health Care Proxy completion rates were not assessed.[xxv]

In February 2008, Excellus conducted a third wave of the Employee Healthcare Decisions Survey (Employee Survey) to see whether employee knowledge and behavior regarding advance directives had changed over the past two years. The survey instrument and methodology were nearly identical to that used in the previous, 2006 Employee Survey. In both studies, an online methodology was used. On February 8th, all 4,343 Excellus Health Plan employees were sent an email inviting them to participate in the survey. Two follow-up emails were sent to non-respondents within two weeks of the initial mailing to help improve the response rate. Of the over 4,300 surveys sent to employees, 2,314 or 53% responded, about the same response rate reported in 2006 (52%). The response rate obtained in the 2002 Survey was significantly lower (only 35%), even though the survey tool used in that survey was much shorter (only 6 questions, compared with 23 questions in the 2006 and 2008 Surveys). However, the 2002 Survey was conducted by mail (not online) and only one survey was mailed to employees.

Some key findings include:

- During the past two years, the completion rates for Health Care Proxies and Living Wills have risen significantly within the Excellus employee population. Overall, the completion rate for Health Care Proxies now stands at about 43% for employees, up from 34% in 2006.

- Significant regional differences exist in completion rates for Health Care Proxies, a finding that was observed in the Community Survey as well. Completion rates among employees are highest in WNY (51%) and Rochester (45%) and lowest in Utica (31%).

- The completion rates for employees are somewhat higher than those of the upstate community, after adjusting for differences on key demographic factors known to significantly impact completion rates (e.g., age, region, gender).

- Comparisons of the employee results with those obtained from recent national surveys (e.g., AARP Bulletin, Pew Research) are difficult to make, due to significant differences between the demographics of our employee population and the populations targeted in the national surveys. The demographics of the populations surveyed are quite different, particularly with regard to age which has been shown to be a key factor in driving completion rates.

- Evidence from both the Employee and Community Surveys suggests that regional differences in completion rates may be driven, in part, by physician communications with patients. In both surveys, the highest rate of discussion with doctors occurred in Rochester while the lowest rate was observed in Utica.

- Further, evidence from the Employee and Community Surveys suggest community education makes a difference. Higher completion rates are present in regions where community education efforts have been initiated.

- Some evidence suggests that young adults (ages 18 to 24) can respond to behavioral interventions and be motivated to take action and complete a Health Care Proxy. Completion rates among young adult (ages 18 to 24) employees (25%) were noticeably higher than young adults in the community (9%).

- Personal experience with the end-of-life care of others appears to play a major role in the decision to designate a Health Care Proxy. Nearly half of those who had completed a Health Care Proxy form mentioned personal experience as playing a significant role in their decision to act.

- The results support the view that an advance care planning employee campaign that utilizes interventions that include incentives can motivate employees to take action to complete a Health Care Proxy.

CCCC Process Measures:
In addition, Excellus BCBS has a number of tracking and evaluation mechanisms to track and continuously improve the CCCC Program, including:

- number of booklets distributed
- number of web downloads made
- number of CCCC presentations given
- number of attendees at each presentation is tracked
- effectiveness of the CCCC workshop using the *Health Care Proxy Readiness Form* designed by Dr. Patricia Bomba, Dr. Andrew Doniger and Dan Vermilyea
- *CCCC Program* and *CCCC Facilitator Training Workshop* Evaluation forms

Number of booklets distributed:
To date, more than 350,000 copies of the Advance Care Planning booklets have been distributed throughout our service area. In addition, the booklet is available to download on both the corporate and community web sites.

During the prominent media exposure of the Terri Schiavo situation, Excellus BCBS distributed more than 22,000 copies of the booklet. In the same time period, an additional 28,176 Advance Care Planning booklets were downloaded from the web.

Number of web downloads made:
With the growth of the Initiative and concrete projects, the community web site www.CompassionandSupport.org was enhanced and launched on July 31, 2007. Google Analytics confirms a total of 24,371 visits from 17,829 unique visitors from 100 countries from inception through April 19, 2008. 22,209 visits from across the country, including 60% from New York State. Further, 166 title pages on this site were viewed a total of 85,826 times; 10 title pages containing "advance care planning" were viewed 5,431 times.

Number of CCCC presentations given, Number of attendees and Number of trained facilitators:
Since the CCCC workshop was created and as on December 2007, a total of 5,521 individuals attended one of the 241 free CCCC workshops offered to community members, internal employees and healthcare professionals. 422 trained facilitators are available throughout our service region to provide workshops and 1 on 1 facilitated discussion. The workshops were held throughout the community, including the workplace, senior living communities, houses of worship, community organizations, doctor's offices, hospitals and nursing homes. Trained facilitators track workshops but have not provided data on the number of 1 on 1 facilitated discussion.

Effectiveness of the CCCC workshop using the Health Care Proxy Readiness Form:
Data on the CCCC Workshop shows the workshop format motivates individuals to complete an advance directive; view CCCC Pilot Results.
For those who attend a CCCC Workshop, 48% of those in attendance had an advance directive; 55% had an advance directive 6-8 weeks later. The difference is statistically significant (p-value = .01).

CCCC Program and CCCC Facilitator Training Workshop Evaluation forms:
Evaluations have consistently received high scores, generated positive feedback and interest in further training.

Needs Assessment for Actionable Medical Orders for Seriously Ill Patients

Workgroup 2 Ensuring patient wishes are identified and honored at all sites of care

Humane care for those approaching death is a social obligation not adequately met in the communities we serve. Too often, death is viewed as a medical failure rather than the final chapter of life. As a result, many people fear a protracted, technologically-overtreated death, abandonment during a time of need and profound suffering of self and family. Currently, conversations about death are too frequently avoided until a crisis occurs, resulting in inadequate Advance Care Planning and patient preferences not being known or honored. Surveys reveal more than 70 percent of surveyed Americans indicated that they wish to die at home. Yet, only 25 percent of Americans die in their home and 75 percent die in institutions[xxvi].

Since the Patient Self-Determination Act passed in 1991, the current system of communicating end-of-life care wishes solely using traditional advance directives, such as the living will, has proven insufficient. Traditional directives require individuals to recognize the importance of Advance Care Planning, understand medical interventions, evaluate personal values and beliefs and communicate their wishes to their agents, loved ones, physicians and health care providers. Unfortunately, even if this happens, traditional directives are often overlooked, ignored or not communicated once the individual enters the health care system.

Too often, advance directives are ignored in favor of continuing life-sustaining treatments out of fear of a negligent or wrongful death lawsuit from family and/or loved ones instead of honoring the wishes expressed in the directives. [xxvii] Continuing to administer life-sustaining treatments beyond the patient's wishes is not without risk either. Numerous lawsuits, including Klavan v. Chester Crozier Medical Center et al., Estate of Leach v. Shapiro and Anderson v. St. Francis – St. George Hospital, Inc., found health care professionals can be held liable for medical malpractice, battery and/or negligence if life-sustaining treatments provided contradict expressed patient wishes[xxviii].

Further, there are significant regional variations in the cost of care, percentage of deaths occurring in hospitals and other measures of end-of-life care. High-spending regions reveal more inpatient-based and specialist-oriented care. However, there is no improvement in health outcomes, including mortality rates, quality of care, access to care or patient/family satisfaction.[xxix]

A study by W.M. Tierney et al. found that elderly patients with chronic illnesses that discussed advance directives with their primary care physicians showed significantly greater satisfaction with their care than those who did not have advance care planning discussions. The strongest predictor of satisfaction with care was the presence of advance care planning discussions. [xxx]

Unfortunately, traditional directives like the living will apply to future circumstances, require further interpretation by the agent and health care professionals and do not result in actionable medical orders. The situation is further complicated by the difficulty in defining "terminal" or "irreversible" conditions and accounting for the different perspective of physicians, agents and loved ones. For example, a patient with dementia nearing the end-of-life eats less, has difficulty managing secretions, aspirates and often develops pneumonia. While end-stage dementia is "terminal", pneumonia may be potentially "reversible". Decisions regarding care depend on interpretations of prior conversations, physician's estimates of prognosis, and, possibly, the personal convictions of the physician, agent and loved ones. The presence of the living will does not help clarify the patient's wishes in the absence of antecedent conversation with the family, close friends and the patient's personal physician. A study by Ditto et al. discovered that family members correctly identified the patient's wishes less than 70 percent of the time. Additionally, family members were two to three times more likely to choose over-treating versus under-treating the patient.[xxxi]

Medical Orders for Life-Sustaining Treatment (MOLST) Program
New York State's Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program
Workgroup 2 Intervention - "Actionable Medical Orders" for Seriously Ill Patients

The MOLST Program is designed to improve the quality of care people receive at the end of life and is based on effective communication of patient wishes, documentation of medical orders on a brightly colored form and a promise by health care professionals to honor these wishes.

Effective communication between the patient or legally designated decision-maker and health care professionals ensures decisions are sound and based on the patient's understanding of their medical condition, their prognosis, the benefits and burdens of the life-sustaining treatment and their personal goals for care.

MOLST is one of six endorsed POLST Paradigm Programs nationally.

MOLST Program History:
MOLST is consistent with PHL§2977(3) and is used in all counties and all settings statewide. This was accomplished through collaborative work with the NYSDOH and legislative advocacy.

The MOLST Program is a project of the Community-Wide End-of-life/Palliative Care Initiative (Initiative), a community collaborative that focuses on implementation of a set of broad end-of-life/palliative care projects that result in quality improvements in the lives of those facing death.

- View information on the Initiative.
- View outcomes of the Initiative.

Through leadership and administrative support for the Initiative provided by Excellus BlueCross BlueShield, the Initiative, originally based in Rochester, has spread through the Health Plan service region in Upstate New York. With the MOLST Program, the reach of the Initiative extends across New York State. The success of the Program is attributable to partnerships with the New York State Department of Health, statewide professional associations, particularly the Medical Society of the State of New York, and healthcare and community collaborative partnerships throughout New York State.

Short-term goals were set:

- Consistent uniform application of the Medical Orders for Life-Sustaining Treatment (MOLST) program.
- Successful MOLST Community Pilot and adoption of a MOLST as a statewide program.
- Expanded cadre of volunteers prepared to engage in one-to-one and community conversations regarding end-of-life issues, options and the value of advance directives, including the MOLST form.

Short-term goals have been achieved.

Long -term goals were set:

- Informed and prudent use of life-sustaining technologies and intensive care services.
- Greater efficiencies in health care delivery.
- Improved patient and family satisfaction.
- Reduction in costs associated with medical liability and defensive medicine by providing physicians an efficient framework for discussing end-of-life options.

Six key steps were employed in the development and implementation of the Initiative and its projects like the MOLST Program:

1. Define Vision, Mission, Values
2. Employ results-oriented approach
3. Design effective, inclusive coalition membership
4. Create effective leadership
5. Demonstrate strong commitment to purpose
6. Monitor performance

The MOLST Program began with creation of a MOLST Creation Workgroup in Fall 2001. The form was completed in November 2003. MOLST was adapted from Oregon's POLST and integrates NYS Public Health Law. Implementation began on a voluntary basis in Rochester health care facilities shortly thereafter. A broader regional launch in January 2004 resulted in expansion to surrounding counties. As a result of discussion of the MOLST program at the Education for Physicians on End-of-life Care (EPEC) conferences sponsored twice annually in Upstate New York by Excellus BlueCross BlueShield, EPEC faculty and participants advocated for implementation in other regions in Upstate New York. Community consensus on the use of the MOLST program in Onondaga County was achieved in September 2004 and implementation of MOLST began in hospitals and long-term care facilities in Spring 2005. Interest in initiating the program has been raised in Utica, Cooperstown, Buffalo and other areas of Western New York and is currently underway. Expanding awareness of the MOLST program in Downstate New York is a result of professional collaborations in state organizations, through the Internet and Web sites and through attendance at the Honoring Patient Preferences, The Role of Medical Orders for Life-Sustaining Treatment (MOLST) Conference held in November 2005 in Rochester and collaborative work of the New York State Department of Health and the Greater New York Hospital Association.

As regional adoption ensued, simultaneous collaboration with NYSDOH began in March 2004. As a result, a revised form consistent with New York State Law was approved by the New York State Department of Health (NYSDOH) for use as an institutional DNR in ALL health care facilities throughout New York State in October 2005. NYSDOH sent a Dear Administrator Letter (DAL) on January 17, 2006 confirming its approval. View the DAL Letter. This approval did not require legislative action but achieved significant growth in the MOLST Program across the state.

With passage of the MOLST Pilot Project Legislation (PHL § 2977(13)) (2005) and the Chapter Amendment (2006), New York State Department of Health (NYSDOH) approved the MOLST for use in the community as a Nonhospital Do Not Resuscitate (DNR) and Do Not Intubate (DNI) in Monroe & Onondaga counties. A Monroe and Onondaga Counties MOLST Community Implementation Team (M & O TEAM), led by Dr. Bomba with administrative support from Excellus BlueCross BlueShield, was formed to oversee the pilot. A detailed work plan and timeline was prepared and commitment to the development of several final products was confirmed. View the M & O Team.

Target performance outcome measures were established including:

1) New York State will amend public health law and make MOLST permanent and statewide
2) Patient preferences will be honored at the end-of-life.

Several process measures were created. Data sources were identified. Regular reporting of the data to the M & O Team and the New York State Department of Health was operationalized.

In addition to collaboration with the New York State Department of Health (NYSDOH), the MOLST Community Implementation Team partnered with the Medical Society of the State of New York (MSSNY), the Healthcare Association of New York State, New York State Health Facilities Association Ins (NYSHFA), the New York Association of Homes and Services for the Aging (NYASHA), the Hospice and Palliative Care Association of New York State (HCPCANYS), New York State Office for the Aging (NYSOFA), New York State Society on Aging (NYSSA), New York State Bar Association (NYSBA), the Greater New York Hospital Association (GNYHA), and other professional associations, health care facilities, systems and agencies across NYS. View a full list of collaborators.

A successful MOLST Pilot Project resulted in Governor David Paterson signing into law a bill that made MOLST permanent and statewide, thereby changing the scope of practice for EMS across New York State. MOLST is consistent with PHL§2977(3) and cannot be altered. MOLST has been reviewed annually since 2005, complies with New York State Public Health Law, and has been adapted to meet clinical needs. View the press release.

Legal Barriers Overcome:

Nonhospital DNR Law before MOLST (PHL § 2977) dictated a DNR order must be on "standard form" issued by the Department of Health; by contrast, a hospital-based DNR order can be on any form. The "standard form" is a one page form with little detail beyond instruction not to resuscitate. Further, the Nonhospital DNR can be honored ONLY if patient is in FULL cardiopulmonary arrest. If the patient is NOT in full cardiac or respiratory arrest, FULL treatment must be provided. DNI was NOT covered in Nonhospital DNR law.

The MOLST Pilot Project Legislation (PHL § 2977(13)) permitted the New York State Department of Health to authorize using the MOLST form in lieu of the Nonhospital DNR in Monroe and Onondaga Counties. The "standard form" did NOT need to be used in pilot counties. The Regional Pilot in Monroe and Onondaga Counties was approved by NYSDOH in October 2005.

Because DNI was not covered in Nonhospital DNR Law (Public Health Law § 2977), passage of the 2006 Chapter Amendment permitted EMS to honor Do Not Intubate (DNI) instructions prior to full cardiopulmonary arrest in Monroe and Onondaga Counties during the MOLST Community Pilot. The law provided for a carve-out for persons with Mental Retardation (MR) and Developmental Disabilities (DD) *without capacity*. Public Health (PH) DNR law for persons with MR/DD *without capacity* remained the same as it would be without MOLST. Persons with MR/DD *with capacity* could complete a MOLST form.

In Pilot counties, EMS personnel followed orders on the MOLST form for individuals living in Monroe and Onondaga counties. For individuals living in Monroe and Onondaga counties, a completed MOLST form could replace the NYS Nonhospital DNR form. For individuals living outside Monroe and Onondaga counties, the NYS Nonhospital DNR form had to be completed in addition to the MOLST. A MOLST form provided "clear and convincing evidence" to EMS Medical Control outside Monroe and Onondaga counties.

A successful MOLST Pilot Project resulted in Governor David Paterson signing into law a bill that made MOLST permanent and statewide, thereby changing the scope of practice for EMS across New York State. MOLST is consistent with PHL§2977(3) and cannot be altered. MOLST has been reviewed annually since 2005, complies with New York State Public Health Law, and has been adapted to meet clinical needs. View the press release.

State Laws and Regulations:
MOLST is consistent with PHL§2977(3) and can be used in all settings statewide. View pertinent legislation and regulation.

Facility Implementation of MOLST Program:
Use of the MOLST form has been integrated into policies and procedures regarding advance care planning at area hospitals and long-term care facilities. Permission has been granted to share sample policies and procedures with other systems throughout the state. View samples of policies and procedures.

Management:
The Community-Wide End-of-life/Palliative Care Initiative provides oversight of the MOLST Program. Statewide development and implementation efforts have been spearheaded by Dr. Pat Bomba, with Excellus BlueCross BlueShield generously providing support for legislative advocacy and administrative support for operations, including development, distribution and fulfillment of MOLST support materials and resources, education and training, quality improvement, monitoring performance and sharing best practices & lessons learned.

MOLST resources can be ordered online by using the order form. The process for ordering MOLST materials has been enhanced as the program has grown and is moving to online ordering.

Training of Health Care Professionals:
To support statewide implementation and training needs, several final products were developed, including, but not limited to:

- MOLST Training Center
- MOLST Training Videos with online CME/CE credits
- Tube Feeding Guidelines developed by the PEGS Workgroup
- Community Conversations on Compassionate Care (CCCC) Video
- Advance Care Planning Clinical Pathways
    - Life Expectancy >1 Year
    - Life Expectancy <1 Year

Funding for production of the MOLST DVD and enhancement of the community web site www.CompassionandSupport.org was obtained through the Medical Society of the State of New York and Excellus BlueCross BlueShield Community Initiatives.

The MOLST DVD was produced to educate and empower patients and families and serve as a standardized training tool for professionals. The MOLST DVD is a statewide initiative presented by the Medical Society of the State of New York and Excellus BlueCross BlueShield in collaboration with the New York State Department of Health and the Monroe and Onondaga Counties MOLST Community Implementation Team. Development was led by the MOLST DVD and Web-based Tools Subcommittee.

The MOLST DVD includes 2 videos and 3 refresher videos:

- "Writing Your Final Chapter: Know Your Choices...Share Your Wishes" is designed to inform patients, families and professionals about MOLST.
- "Honoring Patient Preferences: The Role of Medical Orders for Life-Sustaining Treatment (MOLST) in New York State," an educational video for professionals, provides the core curriculum on MOLST.

Healthcare professionals can earn a maximum of 2.0 free educational credit hours by viewing both videos and completing the MOLST DVD posttest. Follow the simple steps on the MOLST Training Video page.

Professionals are encouraged to share the MOLST DVD with seriously ill patients and their families. The videos and additional information can also be viewed at www.CompassionandSupport.org, specifically at the MOLST Training Center.

Subsequent to passage of the MOLST legislation, a new web page was launched for statewide EMS MOLST Training.

There are many resources available in the Web site's section for Professionals, the Resource Directory, and the References section. Professionals stay informed via the News & Events and Current News. Upcoming opportunities are available at Current Events; online registration is available for Initiative events.

Training for Patients/Families/Community:
The CompassionandSupport Web site is a community Web site dedicated to educating and empowering patients, families and professionals on advance care planning, MOLST, palliative care, pain management and hospice care and related topics. The Web site was developed in 2001 to overcome functional health illiteracy, and was enhanced in 2007. View the Patients & Families section of the Web site.

The award-winning video, *"Writing Your Final Chapter: Know Your Choices...Share Your Wishes"* is designed to inform patients, families and professionals about the MOLST Program.

CQI Projects and Research:

Initially, the project primarily focused on implementation, education and expansion. Excellus BlueCross BlueShield has developed an internal tracking system to monitor the distribution and fulfillment process of MOLST forms and guidebooks. As part of the implementation process, a survey of long-term care facilities in Rochester was done in January 2005 to share implementation issues, barriers and lessons learned with long-term care facilities in Onondaga and other counties.

A MOLST Quality Audit tool was developed to assess accuracy of form completion to support the MOLST Community Pilot. View the Quality Improvement tool. Quality audits were conducted in 2006 and 2007. MOLST Quality Forums were held in both Monroe and Onondaga Counties in January 2008. View the MOLST Quality Forum presentation. Results showed improvement in accuracy of form completion for both DNR and Life-Sustaining Treatment orders. Patient or Health Care Agent consent was present 100% of the times.

With regards to the Community MOLST Pilot Project, performance measures included:

- *Ability of out-of-hospital healthcare providers and first responders to correctly interpret and use the MOLST form*
- *Appropriate use of both Non-hospital DNR and MOLST forms by EMS regarding provision of CPR, intubation and appropriate transfer to hospital in accordance with patient wishes in Monroe and Onondaga Counties*
- *Regional utilization of the MOLST form and program for the appropriate cohort of patients in Pilot Counties*
- *MOLST training for EMS and first responders*

- *MOLST training per facility/organization*
- *MOLST utilization and degree of penetration in facility/organization/per county/region*
- *# MOLST forms and "Supplemental" Documentation Adult and Minor forms*
- *# MOLST educational booklets for health care professionals requests*
- *# MOLST educational brochures for patients and families requests*

Identified data sources include:

- EMS Quality data
- MOLST Facility Implementation Survey data in Monroe and Onondaga Counties
- MOLST Quality Improvement data, utilizing the MOLST QI Audit Tool
- Tracking data on distribution of MOLST educational resources across New York State
- Tracking data on MOLST educational sessions, conferences, training sessions
- Google Analytics on the community web site, www.CompassionandSupport.org.

Results are shared to facilitate best practice. View the Research results.

Initiative Links to National Efforts:

The Initiative aligned its efforts with the National Quality Forum's Preferred Practices for Hospice and Palliative Care[xxxii] published in 2006. Adapted for New York State, the preferred five practices for advance care planning include:

1. Document the designated agent (surrogate decision maker) in a Health Care Proxy for every patient in primary, acute and long-term care and in palliative and hospice care.

2. Document the patient/surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as condition changes.

3. Convert the patient treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital, i.e., the Medical Orders for Life-Sustaining Treatment—MOLST, a POLST Paradigm Program.

4. Make advance directives and surrogacy designations available across care settings

5. Develop and promote healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals (e.g. Respecting Choices and Community Conversations on Compassionate Care)

---

[i] Means to a Better End: A Report on Dying in America Today, November 2002, p.9.

[ii] http://assets.aarp.org/rgcenter/il/getting_ready.pdf. Last accessed April 11, 2008

[iii] http://people-press.org/reports/pdf/266.pdf Last accessed April 11, 2008

[iv] Ott B. B. Advance Directives: The Emerging Body of Research. American Journal of Critical Care. 1999; 8(1) wew. Last accessed February 11, 2006.

[v] Dexter P. R., Wolinsky F. D. Gramelspacher G. P., Zhou Z. H., Eckert G. J., Waisburd M., Tierney W. M. Effectiveness of Computer-Generated Reminders for Increasing Discussions about Advance Directives and Completion of Advance Directive Forms. Annals Intern Med.1998; 128(2):102-110.

[vi] Wenger N. S., Kanouse D. E., Collins R. L., et al. End-of-life discussions and preferences among persons with HIV. JAMA, 285:2880-7, 2001.

[vii] Emanuel L. L., Barry M. J., Stoeckle J. D., Ettelson L. M., Emanuel E. J. Advance directives for medical care—a case for greater use. N Engl J Med. 1991; 324:889-895.

[viii] Gordon N. P., Shade S. B. Advance Directives Are More Likely Among Seniors Asked About End-of-Life Care Preferences. Arch Intern Med. 1999; 159:701-704.

[ix] Hahn M. E. Advance Directives and Patient-Physician Communication. MSJAMA. 2003; 289:96.

[x] Morrison, R. S. and Meier, D. E. High rates of advance care planning in New York City's elderly population. Arch Intern Med. 2004 Dec 13-2004 Dec 27; 164(22):2421-6.

[xi] Bomba, P. A. Advance care planning along the continuum. Case Manager. 2005 Mar-2005 Apr 30; 16(2):68-72.

[xii] Wissow, L. S.; Belote, A.; Kramer, W.; Compton-Phillips, A.; Kritzler, R., and Weiner, J. P. Promoting advance directives among elderly primary care patients. J Gen Intern Med. 2004 Sep; 19(9):944-51.

[xiii] Briggs, L. Shifting the focus of advance care planning: using an in-depth interview to build and strengthen relationships. J Palliat Med. 2004 Apr; 7(2):341-9.

[xiv] Schwartz, C. E.; Wheeler, H. B.; Hammes, B.; Basque, N.; Edmunds, J.; Reed, G.; Ma, Y.; Li, L.; Tabloski, P., and Yanko, J. Early intervention in planning end-of-life care with ambulatory geriatric patients: results of a pilot trial. Arch Intern Med. 2002 Jul 22; 162(14):1611-8.

[xv] Ott B. B. Advance Directives: The Emerging Body of Research. American Journal of Critical Care. 1999; 8(1) wew. Last accessed February 11, 2006.

[xvi] Dexter P. R., Wolinsky F. D. Gramelspacher G. P., Zhou Z. H., Eckert G. J., Waisburd M., Tierney W. M. Effectiveness of Computer-Generated Reminders for Increasing Discussions about Advance Directives and Completion of Advance Directive Forms. Annals Intern Med.1998; 128(2):102-110.

[xvii] Wenger N. S., Kanouse D. E., Collins R. L., et al. End-of-life discussions and preferences among persons with HIV. JAMA, 285:2880-7, 2001.

[xviii] Emanuel L. L., Barry M. J., Stoeckle J. D., Ettelson L. M., Emanuel E. J. Advance directives for medical care—a case for greater use. N Engl J Med. 1991; 324:889-895.

[xix] Gordon N. P., Shade S. B. Advance Directives Are More Likely Among Seniors Asked About End-of-Life Care Preferences. Arch Intern Med. 1999;159:701-704.

[xx] Hahn M. E. Advance Directives and Patient-Physician Communication. MSJAMA. 2003; 289:96.

[xxi] Morrison, R. S. and Meier, D. E. High rates of advance care planning in New York City's elderly population. Arch Intern Med. 2004 Dec 13-2004 Dec 27; 164(22):2421-6.

[xxii] http://www.compassionandsupport.org/pdfs/research/2002_Employeee_Health_Care_Decisions_Survey_Report.pdf Last accessed April 11, 2008

[xxiii] http://www.compassionandsupport.org/pdfs/research/2006_Employee_Health_Care_Decisions_Survey_Results_Report.pb.092406.FINAL.pdf Last accessed April 11, 2008

[xxiv] http://assets.aarp.org/rgcenter/il/getting_ready.pdf Last accessed April 11, 2008

[xxv] http://people-press.org/reports/pdf/266.pdf. Last accessed April 11, 2008

[xxvi] Means to a Better End: A Report on Dying in America Today, November 2002, p. 13.

[xxvii] http://www.physiciansnews.com/law/999martindv.html

[xxviii] http://www.physiciansnews.com/law/999martindv.html

[xxix] http://www.dartmouthatlas.org/ Last accessed April 24, 2008.

[xxx] Tierney, WM et al. "The Effect of Discussions about Advance Directives on Patients' Satisfaction with Primary Care." Journal of Internal Medicine 16, January 2001, pp. 32-40.

[xxxi] http://www.ahrq.gov/research/may01/501ra14.htm

[xxxii] http://www.qualityforum.org/publications/reports/palliative.asp Last accessed April 11, 2008

Senator WHITEHOUSE. Thank you, Dr. Bomba. Before we go to questions I would like to call on Susan Collins of Maine, my colleague, who has graciously joined us. If she'd like to share a few words, I'd be gratified.

STATEMENT OF SENATOR COLLINS

Senator COLLINS. Thank you very much. I want to pride your decision to hold this hearing and The Chairman.

I've worked so long on end of life care with my colleague from West Virginia. This is an issue that we joined together on my very first year in the Senate. I'm delighted that he's joined us as well.

Mr. Chairman, in the interest of time since I had to be at another hearing I'd ask permission to have my full statement in the record.

[The prepared statement of Senator Collins follows:]

PREPARED STATEMENT OF SENATOR SUSAN COLLINS

I want to thank the Chairman and my colleague from Rhode Island for calling this morning's hearing to examine ways that we can improve how we care for people at the end of their lives.

Noted Princeton health economist Uwe Reinhardt once observed that "Americans are the only people on earth who believe that death is negotiable." Advancements in medicine, public health and technology have enabled more and more of us to live longer and healthier lives. 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.

The fact is that dying is a universal experience. 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.

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

I have worked with my dear friend and colleague from West Virginia, Senator Rockefeller, on a number of initiatives designed to improve the way our health care system cares for patients at the end of their lives.

The Medicare physician fee-fix bill passed by the Congress earlier this year includes a Rockefeller bill that I cosponsored that requires physicians to include a discussion regarding advance directives during the initial "Welcome to Medicare" physician visit to which all Medicare beneficiaries are entitled.

I have also joined the Senator from West Virginia in introducing the broader Rockefeller-Collins Advanced Planning and Compassionate Care Act which is further intended to facilitate appropriate discussions and individual autonomy in making decisions about end-of-life care.

For example, our bill requires that every Medicare beneficiary receiving care in a hospital, nursing home, or other health care facility be given the opportunity to discuss end-of-life care and the preparation of an advance directive with an appropriately trained professional within the health institution. The legislation also requires that, if the patient has an advance directive, it must be displayed in a prominent place in the medical record so that all the doctors and nurses can clearly see it.

The legislation also establishes a telephone hotline to provide consumer information and advice concerning advance directives, end-of-life issues, and medical decision making. It establishes an End-of-Life Advisory Board to assist the Secretary of Health and Human Services in developing outcome standards and measures to evaluate end-of-life care programs and projects.

Mr. Chairman, patients and their families should be able to trust that the care they receive at the end of their lives is not only of high quality, but also that it respects their desires for peace, autonomy and dignity. On Monday, I had the opportunity to visit the Hospice of Southern Maine's Gosnell Memorial Hospice House which is the product of an extraordinary collaborative effort to improve the quality of end-of-life care for patients in Southern Maine and their families.

In most cases, hospice care enables dying patients to remain in the comfort of their own homes, free from unnecessary pain and surrounded by friends and families. The Gosnell Memorial Hospice House provides an alternative for those individuals for whom care in the home is not longer sufficient. It provides a comfortable and attractive home-like setting for hospice patients and their families where they can receive advanced professional palliative and end-of-life care in their final days. The facility is making such a positive difference for so many patients and their families and should serve as a model for the rest of the nation.

Again, Mr. Chairman, I thank you for calling this hearing which will give us the opportunity to further examine these important issues.

Senator WHITEHOUSE. Without objection.

Senator COLLINS. Thank you. I'll just make a couple of comments. On Monday of this week I visited a new hospice house in Southern Maine. What a wonderful place that was to be for people who are dying and their families.

I was so impressed with the care, the palliative care, being provided at this facility. It was a tremendous, warm place where the wishes of the patients were accommodated to the point that one patient's greatest wish was to die outside. So what they did is wheeled the bed outside in a lovely garden so that this individual's last wish could be accommodated.

Even more of a benefit was the peace that it brought to the family members. It was an extraordinary facility. But here is what is at risk.

Starting October first, unless we act to block it, there are going to be cuts made in reimbursements to home care and hospice care. This makes no sense at all by every study and every measure home healthcare and hospice care is not only a more compassionate way for many Americans to spend their final days, but it's less expensive. For CMS and this Administration to target home healthcare and hospice care for more than two billion dollars worth of cuts over the next 5 years makes no sense at all.

So I just want to make a plea for my colleagues to join in figuring out a way for us to block this before it goes into effect and time is short. It's October first.

A quarter of all Medicare dollars go toward end of life care, high tech care in hospitals where people are tethered to high cost machines even though there's no hope of curing. At that point in life most people want palliative care, 80 percent as our witnesses are indicated. Yet in most cases they die in hospital settings. This simply doesn't make sense.

We're not honoring the wishes of people at the end of their lives. It's costly to care for them in high tech settings. So whether you look at it as an economic issue or as an issue of compassion, we need to change. We're certainly going in the wrong direction if we're going to cut reimbursements for home healthcare and hospice care.

Let me just end by one of my favorite quotes on this issue. It's by a noted healthcare economist, Uva Rinehart. I think he's at Princeton.

He once observed that Americans are the only people on Earth who believe that dying is negotiable. Obviously it isn't negotiable. But surely what is negotiable and what we should honor are people's wishes as to the setting in which they die. I believe the vast majority of Americans would rather be surrounded by family and friends, free from pain and comforted in a setting of a home with hospice care or a hospice facility which gives you a little higher level of care. So let's direct our reimbursement policies toward that goal.

Again thank you so much for the opportunity to make a few—a brief statement on this issue about which I feel so passionately. Thank you for holding this hearing.

Senator WHITEHOUSE. Thank you, Senator Collins. Thank you so much for your passion on this issue. I agree with you.

I suspect that if an alien race came from outer space to see us as humans and they looked at the way people die in this country they would wonder why it is that we choose to torment our dying and why we haven't figured out a better way. It would seem that way, I think, to people not familiar with unintended consequences that have led us to this point.

I'd like to ask a question that some of you have touched on, particularly Ms. Curran and Dr. Meier. As we mentioned when I was speaking before the hearing, I've had two very close experiences with dying, both people who were of great personal dignity and a great desire for personal independence. One was my father, who died at home, peacefully, comfortably and with great dignity.

The other was my grandmother-in-law, who despite fierce determination that she should go on her own terms, because of the way in which she came to the hospital through an emergency medical response, was against her will, intubated. We were not capable of getting her de-intubated, and she died in exactly the way she had urged us to prevent.

For me, my father's death, as sad as it was, was unclouded by any concerns about the way he died. I consider it to be one of the great blessings of my life that it happened that way. For my wife and for her sister, who felt the responsibility of honoring my grandmother-in-law's wishes and who were unable to do so because of those circumstances, I believe that there remained a cloud on their grieving. I think it really does make a very big difference to survivors whether or not they feel that they've been able to help their loved one, as you mentioned Ms. Curran, accomplish their will.

I've told this story. You've told your story. Were you aware of any place in which this has been documented? We're in a building here in which anecdotes are nice, but people like to see a little hard data. Has anybody looked at this in any qualitative way to the extent to which others suffer because somebody else's wishes were denied them at this very vulnerable time?

Ms. CURRAN. One of the things that we measure at Gundersen Lutheran is patient satisfaction outcomes or family satisfaction outcomes with the program. So we have data on how families feel if they've participated in palliative care, hospice care, end of life care planning our model compared to those who don't. We just got recent, very, very recent data right before I came here that shows that there's a significant statistical difference of higher satisfaction with families who get what they need for their loved ones at the time of death.

Senator WHITEHOUSE. Dr. Meier?

Dr. MEIER. Well, actually my colleague, Dr. Teno has done most of the high quality research on this topic. As was just said all the studies that have looked at it, both in the United States and internationally, have shown markedly better satisfaction in, as judged by the family survivors, after receiving palliative care.

Senator WHITEHOUSE. Yeah. Joan's work on this has been phenomenal. I just happen to be familiar with it because we've worked together for so long in Rhode Island.

For her I would move to my second question. I'd like to ask Attorney General Edmondson to comment on it as well. When I first got into this issue it was because of Dr. Teno's information about the extent to which people died in pain and to the extent in which families characterize that pain as agonizing or excruciating, which all seemed unnecessary because we have the medication to treat that.

The first concern was that well it's because of us, you know, prosecutors. Doctors are scared that if the moment of death gets moved forward 30 seconds because of the breathing is depressed by a morphine based drug for instance, that could technically be prosecutable. Therefore everybody has got to be careful about this stuff.

But as we looked into it, what seemed more to be the case was that it was kind of overlooked. If I recall the intervention that had the most effect was to add pain as a fifth vital sign onto charts and direct doctors' attention to it. Then suddenly it all came into play. Family members didn't have to be there fighting with the doctor saying, please, please, please. My loved one is in agony. Can't you do something?

Could you, Joan and Drew comment on that?

Dr. TENO. I think one of the experiences that we got out of doing a very multi-faceted intervention in Rhode Island is that you need to look at this from a community/state partnership. You need to bring multiple groups of people together to think about what are a series of stepped interventions that you need to do to improve end of life care. So as you mentioned the key first step is to make sure someone is measuring pain because if you don't measure it, you're not going to improve it.

A key second step is making sure doctors know how to manage pain or to make sure there's appropriate resources available in the community. For people who are dying in nursing homes one of those very important resources is hospice. This is one of the things that really I'm so pleased by Senator Collin's comments about talking about such an important issue.

If we cut every hospice's budget somewhere around four to 5 percent that's going to effect access to end of life care in nursing homes. It's going to have a disproportionately effect on these family members. These family members, quite poignantly will tell you that when hospice becomes involved, they no longer had to fight for adequate pain control.

Yes, this does impact the family. Years later they will recall that it's almost like a post traumatic stress disorder with these families, almost like they went to Vietnam and they came back. They will recall with such sadness on how their mother had to struggle and be in pain while dying. It burns a permanent record that mars them for the rest of their life.

Senator WHITEHOUSE. Attorney General Edmondson you used a very good word, permeable, about trying to interrupt the heartbreak between curative medicine and palliative hospice medicine that the present Federal regime seems to require. Would you like to comment a little further on that, on the context of the pain question whether you've gone the vital signs route and whether that helped?

Mr. EDMONDSON. One of the things that's very difficult and it's very understandable is to get doctors to say that their patient is going to die because that's not what they're geared to do. Doctors are geared to save lives. Doctors are geared to cure. It's very hard to get them to cross over that threshold and realize that the death of a patient is not a failure. It's a natural process of life.

Again, my wife, the medical social worker, reversed the question when she was in a hospital setting she would ask the doctor would you be surprised if this patient died in the next 6 months or in the next year. That changes the perspective. It changes the attitude as to what kind of services are supposed to be available.

On pain and on palliative care we heard many statistics during our listening conferences. They ranged but there's still high numbers at the bottom ranges. Thirty to 40 to 50 million Americans, in pain, today that could be managed and is not being managed, 30 to 40 percent of the residents of nursing homes, in pain that could be managed and is not being managed.

One of the barriers to that is the perception by some doctors that if they prescribe oxycontin instead of Tylenol Number Three, they're more likely to become under investigation by either the State Narcotics Bureau or a Medical License Review Board or the DEA. We've been working for the last two or three years with DEA to try to change those perspectives, and to convince the medical community that if they prescribe appropriately, if they chart, if they do examinations, they do not have to risk investigation or prosecution by narcotics agents.

The paucity of doctors who have been prosecuted, the very small percent, are still on the front page of the paper and scared the bejesus out of the rest of the medical community. So we are also encouraging DEA and local law enforcement when they have to have one of those prosecutions to take the next step and explain why that doctor was practicing out of the mainstream and why this should not be a warning to doctors that are prescribing appropriately.

Senator WHITEHOUSE. Thank you, Attorney General.

Chairman Kohl?

The CHAIRMAN. Thank you very much. Ms. Curran, in LaCrosse at Gundersen Lutheran where you work, you have one of the best systems in the country at providing patients with the care that they want at the end of their lives. Can you give us some of the central elements of that system?

Ms. CURRAN. The system starts with every patient. It's part of our assessment process. When patients come into the medical center regardless of their age, as long as they're an adult, we ask about whether or not they have an advance care plan in place. So it's part of the assessment process. Through education to our medical staff and again, the acceptance in the community believe this is the right thing to do for our patients.

In addition to that we have a long history of palliative care in our organization. The other thing that we pride ourselves in is that we're very close to our patients, listening to what they want for care. So, those are probably the biggest steps.

Is No. 1, having advance care planning as part of their medical assessment. Even in my routine appointment this year, even though my advance directives have been on file for a number of years. One of the things my practitioner said to me was, do you have any changes you would like to make to your advanced care plan. That's part of our routine, I mean, that's part of our routine assessment of our patients.

In addition to that we have a long history of knowing how to facilitate these discussions with families and friends. So even though the program in its inception in 1986 started with the pastoral care department primarily working with people that had terminal illnesses or prognoses of terminal illnesses, that's moved onto in the community whether it's been with churches, social workers, practitioners themselves. It permeates the whole organization as well as our community. So those are probably the strongest elements of our programs.

Someone talked about measuring results. We actually have two studies that we have done on two people who have advance care planning in place? Is it where they need it at the site of care? When they need it? Are physicians or medical professionals honoring that care?

We just finished our 10 year follow up and our statistics are astounding and the fact that we have over 90 percent in all of those categories. In one of them they're 99.

The Chairman. Thank you very much. Thank you, Mr. Chairman.

Senator WHITEHOUSE. Chairman Rockefeller?

Senator ROCKEFELLER. Thank you, Senator Whitehouse and Chairman and Susan Collins. Susan Collins and I have, since the—what was it, the 105th Congress which was some 50 years ago. [Laughter.]

Have introduced a bill to make people more sensitive to the wishes of people who—and it's never gotten anywhere. It's never gotten any attention. We may have had a hearing. If there was, we weren't on the Committee.

This is the course. Dana Farber, in 2005, you know they, obviously there's a superior hospital. They had 90 percent of their medical students and residents surveyed, had positive views of physician's responsibility to help patients at the end of life prepare for death. Fewer than 18 percent of all of them reported receiving any formal end of life care or training on palliative care education.

When geriatricians become geriatricians often find it doesn't work enough or pay enough and go off into other fields is a major thing. Nobody's addressed this. So the number of geriatricians, can that be made up by social workers and everybody else?

My mother spent 12 years dying from Alzheimer's and was in the hospital and finally made her wishes—she had all the advance directives and everything needed. All four of her children agreed with what her wishes were. The hospital wouldn't release her, for reasons which you indicated. They just wouldn't release her because of the Hippocratic Oath, "Do no harm."

That's the question I'd like to ask whoever would like to respond to it, whichever one of you would like to respond to it. How do you describe, "Do no harm." I mean "do no harm" to the patient. "Do no harm" to the patient in the case of Alzheimer's, but not necessarily in other cases where there's acute pain. "Do no harm" to people who can't feel pain and therefore what harm could you be doing them.

While in the meantime in states like West Virginia, families are coming back, their children are coming back from other states. Moving back, bankrupting themselves so that, you know, their children and then, you know, this constant pattern. So what does "do no harm" and what is the point at which "do no harm" crosses the conventional understanding of what that means into another doing harm intending not to. Please.

Incidentally I'm thrilled with what happened to you yesterday. But I also noticed that the example that you gave was an example that worked. Your entire testimony was about an example that worked. My mind is full of cases that didn't work.

Dr. MEIER. I gave this example, because it worked after 63 days. Mrs. J had 63 days of unremitting suffering with "do no harm" type care, until a palliative care consult was eventually called. So yes, it worked, but rather late.

So I think the main point is that you cannot expect physicians and nurses to relieve suffering which is part of the Hippocratic Oath, if they have never been taught how to do so. I went to medical school at Northwestern, 4 years of med school, 3 years of internal medicine residency, 2 years of geriatrics fellowship, 9 years of training at the best institutions in this country. Oregon is where I did my residency, actually and fellowship, without a single lecture on how to manage pain. Not one. No, it was never on the curriculum.

So if you look around at these levels of excruciating and tolerable pain in the community, in the nursing home, in the hospital, it's very simple. None of us ever learned how to do anything about it. Why is there no medical education focused on this?

Part of it is that it's not required by the accreditation bodies that accredit medical schools and residency programs. Part of it is that there's nothing to allow us to create a pipeline of faculty in palliative medicine to teach this to future generations of doctors and nurses because we can't get any slots because of the cap. Part of it is that we can't get people to enter this field in teaching hospitals because there's no way they can get grant support. They can't survive.

So how we fund research, how we fund medical education, how we assure a pipeline of experts in this field influences the training that your future physicians and nurses will get. If they don't have the right training, you can't blame them for not knowing what they're doing about the suffering.

Senator ROCKEFELLER. Even if they do have the right training, I don't know how many bills we passed, probably you and I Susan, Jack Danforth and I, you know the chart is at the end of the bed, one of you were talking about were in magisterial form, ignored.

Dr. MEIER. But if the patient is in pain, but the doctor literally does not know how to prescribe morphine, they'll ignore it. If the doctor does not know what to do about the problem, they'll move on to something they do know how to do.

Senator ROCKEFELLER. How does a doctor not know how to issue?

Dr. MEIER. They weren't taught.

Senator ROCKEFELLER. Morphine?

Dr. MEIER. In literally 9 years of training I never prescribed morphine nor did I see it prescribed. I did teach myself at the age of 45 how to manage pain having been on a faculty of a major medical school for many years before that.

Senator ROCKEFELLER. So then do the various medical associations of hospitals have to sort of, dig in and do some very careful planning? I mean, why—

Dr. MEIER. I know it's inconceivable that doctors are not taught to manage pain, but it's a fact.

Senator ROCKEFELLER. Yeah. I know. I totally believe you. I also believe in community work, community service. I believe that relatively low pay is a very good thing if you teach firefighters all the rest of it. Senate is debatable.

The geriatricians, training to be geriatricians and then stopping being geriatricians because they can't make enough money and they want to go onto something else just makes me think of what's going on up in New York somewhere. It makes me very angry. I'd like to have somebody explain to me why this is so. Why are they dropping out?

Dr. MEIER. Because they graduate from medical school with a quarter million dollars in debt and they can—the average salary for a geriatrician in this country is $115,000 dollars a year. The average salary for an orthopedic surgeon is $600,000 dollars a year. There's your explanation.

Senator ROCKEFELLER. Does that—do they take a Hippocratic Oath?

Dr. MEIER. Everyone takes the Hippocratic Oath.

Senator ROCKEFELLER. Well. Thank you, Mr. Chairman.

Senator WHITEHOUSE. Senator Collins.

Senator COLLINS. Dr. Meier, I want to follow up on the discussion you just had with the rest of the panel by asking a broader question. That is to what extent do reimbursement policies, whether they're Medicare, Medicaid or private insurers' influence how end of life care is handled? We've just heard how decisions to specialized are influenced by financial factors.

Look at reimbursement policies for me. Do our current reimbursement policies under Medicare, Medicaid and BlueCross BlueShield and the private insurers actually encourage rescue care over palliative care? What kinds of changes should be made in reimbursement policies so that we're not biasing the kind of care provided toward rescue care over palliative care?

We'll start with you, Ms. Bomba.

Dr. BOMBA. Thank you. I would say that there's a significant impact because we really have traditionally followed what Medicare does. Medicare basically looks at action. It really does not fund compassion, the conversation that is needed to be able to have the discussion on an advance care planning that we've talked about this morning, particularly with seriously ill patients and then translate those into medical orders.

I would give examples of where you can make changes that we did in our own health plan. Palliative medicine physicians have only become recognized by the American Board of Medical Specialists recently. Back in 2001 we recognized we could not develop palliative medicine programs in our communities across Upstate New York without really encouraging and paying providers.

So we set up an interim certification process using criteria that we developed and the American Board of Hospice and Palliative Medicine. We were able to then grow that base of providers. We were the first health plan that began to pay physicians for this type of activity.

So that's an example of where we can make a difference. We're trying to develop a reimbursement model now to be able to look at enhancing the reimbursement for primary care physicians, for geriatricians, for hospitals, for people that would have these conversations, not only in the hospital with hospital based palliative medicine, but in the offices, in the home, in nursing homes. Some of the barriers—

Senator COLLINS. Excuse me for—but I want to make sure I get everybody else's.

Dr. BOMBA. Yes. So some of the barriers end up becoming how do we link it in developing a system that mirrors Medicare. Some of those are barriers that exist today. So we have to be able to turn that around.

Senator COLLINS. Thank you. Mr. Attorney General, did you have anything on this issue?

Mr. EDMONDSON. I mentioned in my testimony I thought it would be good to add a reimbursement rate under Medicare for doctors having end of life discussions with patients. You know, a good doctor will do that, but many doctors are so busy and have such overhead that if it's not reimbursable, it's not going to happen. It's a very important component.

Senator COLLINS. Thank you. Dr. Teno?

Dr. TENO. I think one of the most perverse Medicare reimbursement incentive is the skilled nursing home benefit. It results in multiple hospitalizations and it takes dying people and keeps them on skilled rehab because the nursing home wants to get paid more dollars per day and ends up resulting in a very late referral to hospice. Time and time again, as a Hospice Medical Director, I'm dealing with someone who spent an hour on hospice services.

Second, and I'll conclude at that, is we need to link reimbursement to outcomes and accountability. We need to report about the quality of hospital care. There is no measure that describes the experience of dying in an acute care hospital and they get a free ride on that. They need to be held accountable.

Senator COLLINS. Thank you. Dr. Meier?

Dr. MEIER. The system is perfectly designed to get the results that it gets.

For example, my husband is an interventional cardiologist, an hour of his time doing an angioplasty, which admittedly is a skilled procedure, is several thousand dollars in reimbursement from Medicare. Hour of my time meeting with a distraught family, such as the 90 minutes I described with Mrs. J's family, we billed for the time and we probably got reimbursed about $57 dollars from Medicare. You cannot, through fee for service billing make a living or support a palliative care program under the current Medicare guidelines. So that is a major inhibition to the spread of this demonstratably effective and efficient type of care.

Senator COLLINS. Thank you. Mr. O'Connor?

Mr. O'CONNOR. Thank you, Senator. I don't believe the ABA has a specific position on this. But I would echo what Attorney General Edmondson said that the question becomes whether the doctors under Medicare and Medicaid can get reimbursed for counseling on end of life decisions and then that gets into the whole infrastructure of the reimbursement system that I'm—these folks are a lot more authoritative on that then I would be.

Senator COLLINS. Thank you. Ms. Curran?

Ms. CURRAN. Gundersen Lutheran may be the anomaly in the group. We have a CEO who believes it's all of our responsibilities to lower the cost of healthcare.

To that end we've enacted these different programs. So in the last two years the life at Gundersen Lutheran the average cost is about $18,000 dollars a year. National average is about 25,000 a year.

He certainly gets asked from his board in a fee for service market why would you do less. Our response is because it's the right thing to do for our patients. Everybody needs to take the first step.

I agree with others, that if you reimburse for outcomes and end of life care that you will get a different outcome and a better outcome.

Senator COLLINS. Thank you. Thank you, Mr. Chairman.

Senator WHITEHOUSE. Thank you. I'd like to thank the Senators who joined us. I'd like to thank the witnesses very much.

I will ask one final question before I conclude the hearing that has to do with the POLST Program. Now when we were working in Rhode Island we found that advance directives were drafted in law firms and read in hospitals. There was a huge translation issue between lawyer speak and hospital speak. So we tried to redraft those forms in hospital language so at least there didn't have to be that translation that took place.

I mentioned the issue with my grandmother-in-law, who against her will was intubated because she didn't have the magic bracelet on that nobody knew she needed in order to have her wishes honored in that circumstance. Does the POLST, from your perspective, Mr. O'Connor, solve both of those problems? How would we encourage its further adoption in more states without taking away the authority of individual states to make their own determinations, which I think is something we wish to honor?

Mr. O'Connor?

Mr. O'CONNOR. Let me deal with your first issue first. I have been practicing law for 30 years and have been, ever since they came out in Indiana, have been helping my clients write living wills and healthcare powers of attorney and wondering what happens with those after they're written, you know. I've got a lot of friends who are doctors and they say they don't see them. It's exactly what the studies have now proven to be the case. So a better model needs to be put forward. It has been.

The POLST Paradigm was recently at the ABA meeting in New York. The entire House of Delegates representing over 600 lawyers from around the country voted unanimously in favor of promoting the POLST Paradigm across the country. What can Congress do?

Senator WHITEHOUSE. Does it lend itself to state level differences if there are state level differences? Is it flexible in the sense that states with different plans and different ideas can still make their own decisions?

Mr. O'CONNOR. Almost every state has a similar advance directive laws. There are variations from state to state. We've got charts that show that.

But we believe the POLST Paradigm can be adopted in most states based on their current statutory framework. Just with that addition it doesn't contravene what's already in place for the most part. It's a simple, straight forward form. It promotes communication between the physician and patient.

We feel like there's a good group of states that are considering even now. There's eight states that have enacted it. There's more that are considering it. What Congress can do to promote that? I'm not sure, but we would love it if it could jump in.

Senator WHITEHOUSE. Dr. Bomba?

Dr. BOMBA. I would provide clarity that it doesn't replace traditional directives. We were able to adopt the Oregon model, the POLST Program into New York State, integrating some of the complexities of our law that require capacity, determination and review of DNR orders. We were able to do it.

The traditional directives are for everyone as I said earlier. The POLST Paradigm or the MOLST are for seriously ill patients and they are medical orders signed by a licensed physician in that state. In some states——

Senator WHITEHOUSE. It does trump the statutory obligation of EMS folks to resuscitate?

Dr. BOMBA. In fact, absolutely.

Senator WHITEHOUSE. To intubate?

Dr. BOMBA. To use your grandmother-in-law's example, had she had a goal based discussion it would have been translated into orders that said, do not resuscitate, do not intubate. But with what other choices she would have made regarding antibiotic use, IV fluids, peg tube feedings.

Senator WHITEHOUSE. Her problem was she thought she'd made those choices already, but they couldn't be honored by the technicians who came.

Dr. BOMBA. What would have been different is they would have been written on a medical order form that was hers. It would have been posted to her refrigerator and when EMS arrived they would have looked at the POLST and said, she has had a discussion and this is what she wants.They would follow the orders.

A decade of research in Oregon has shown that people get what they want because they are medical orders. It takes away the ambiguity of the traditional directives. But it doesn't replace them. It should still be a directive for everyone 18 and older to help with the situations that, Mr. Edmondson spoke of and I did, about the young people and avoiding the Terry Schiavos of the world to be able to know who the agent is.

In our state it provides clear and convincing evidence. So people follow it.

Senator WHITEHOUSE. Ok. Well, this has been very helpful. I am extremely grateful to all of you for coming and sharing your expertise and the personal experiences that so much inform what really matters in this question. The record of the hearing will remain open an additional week for those who wish to submit anything further.

But with that, we are and with my gratitude, adjourned.

[Whereupon, at 12:13 p.m., the hearing was adjourned.]

APPENDIX

PREPARED STATEMENT OF SENATOR ROBERT P. CASEY, JR.

I would like to thank Senator Whitehouse for bringing us together today to discuss end-of-life choices and how we can help ensure that an individual's final wishes are honored. This is an extremely difficult time for any family. But as science and medicine advance and we have the ability to extend life far beyond what we thought possible fifty years ago, we must also ensure we are honoring a person's wishes. Advance directives help to do this.

Advance directives are not widely used in this country. According to a 2007 Rand study, only 18–30 percent of Americans have completed any kind of advance directive expressing their end-of-life wishes. That figure increases to 35 percent for kidney dialysis patients and 32 percent for patients with Chronic Obstructive Pulmonary Disorder (COPD).

Even when people do have advance directives, their physicians might not be aware of them. In the Rand study, between 65 and 76 percent of physicians whose patients had an advance directive were unaware of its existence.

State laws on advance directives vary widely. Thirty eight states have developed their own advance directive or living will forms and twelve states will only accept their specific forms as legally valid. Twenty three states impose explicit limitations on a patient's right to forgo life-sustaining treatments or artificial nutrition and hydration.

In Pennsylvania, any "competent person" who is at least 18 years old, or is a high school graduate, or has married can make an advance directive. The advance directive must be signed by the individual or someone they designate if they are unable to sign and two witnesses who must be at least 18 years old. The advance directive becomes operational when the doctor has a copy of it and the doctor has concluded that the individual is incompetent and in a terminal condition or permanently unconscious. The advance directive can be revoked at any time and in any manner; the individual simply must tell their doctor or other health care provider that they are revoking it. Someone who saw or heard the individual revoke the advance directive may also pass this information on.

Clearly, Mr. Chairman, there is still work to be done and I look forward to hearing from the witnesses and working with you and my colleagues on this committee and in the Senate to examine what steps we might take to help in this process.

PREPARED STATEMENT OF SENATOR KEN SALAZAR

Thank you, Senator Whitehouse, for chairing this hearing today and to our esteemed witnesses for being here to share your expertise. I would also like to recognize Oklahoma Attorney General W. Drew Edmondson. Thank you for making the pilgrimage to Washington, D.C. and for your public service.

Today we have an important opportunity to focus on end-of-life health care decisions that many elder Americans make every day. End-of-life health care decisions are difficult, but an exceptionally important part of a patient's health. There are ethical and legal questions that patients must consider and health care providers must contemplate appropriate timing and venues for the discussion with their patient.

Most importantly, end-of-life decisions are important for giving elder Americans the dignity they deserve and spare loved ones the stress of making decisions about their care. However, as reports have shown, few patients document their final wishes, and when they do, their wishes are not always followed. I was surprised to read that a recent RAND study found that between 65 to 76% of physicians whose patients had an advance directive were unaware of its existence.

On July 31, 2008 I introduced a bill entitled the Consumer Health Education and Transparency Act to empower consumers to make informed health care decisions.

An important provision in the bill would require the Secretary of Health and Human Services (HHS) to collaborate with stakeholders to consider how to better prepare Americans for end-of-life care decisions and evaluate end-of-life care spending trends.

In addition, HHS will be tasked with conducting a study to evaluate consumer attitudes and questions regarding end-of-life care decisions and methods for empowering consumers to ensure that their end-of-life care instructions are properly executed. It is my hope that the study will help to identify ways to ensure that the choices patient's make are honored and respected.

Again, thank you Chairman Kohl for facilitating this hearing and to Senator Whitehouse for serving as Chair. I look forward to hearing from our witness on what policies would support wider completion of end-of-life directives.

Excellus

Patricia A. Bomba, M.D., F.A.C.P.
Vice President and Medical Director, Geriatrics

September 28, 2008

Senator Sheldon Whitehouse
Hart Senate Office Building
Room 502
Washington, DC 20510

Dear Senator Whitehouse,

Thank you for the opportunity to testify at the Senate Special Committee on Aging hearing, "Honoring Final Wishes: How to Respect Americans' Choices at the End of Life". It was a pleasure to meet you and share your passion to improve the quality of care individuals receive at the end-of-life.

It was a privilege to share my personal story and underscore the importance of hospice care for patients and their families and the work of the Community-Wide End-of-life/Palliative Care Initiative, a broad based diverse community group based in Rochester, New York, particularly the work related to two complimentary advance care planning programs, namely *Community Conversations on Compassionate Care (CCCC)* and the *Medical Orders for Life-Sustaining Treatment (MOLST) Program, a POLST Paradigm Program.*

CCCC is an advance care planning program designed to motivate all adults 18 years of age and older to complete traditional advance directives like the health care proxy and living will. The CCCC program identifies advance care planning as a process, not just form completion; uses storytelling to discuss death and dying; applies behavioral readiness theory to engage consumers; employs "Five Easy Steps" to complete advance care planning, emphasizing the importance of the conversation; and maintains consistent messaging in all tools and resources. Details on the *CCCC* program, interventions and outcomes are included in the written testimony.

The *CCCC* Program's success is validated by the End-of-Life Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions, Summary Report, 2008 that reported a 42% completion rate across Upstate New York for individuals 18 years of age and older. Regional variation exists with a range of 47% in the Rochester Region to 34% in the Utica Region. The two key variables that appear to influence the higher rates are:

- Physician recommendation
- Community education.

By means of comparison, national metrics for advance directive completion rates include:

- 1991 – Patient Self Determination Act – 20% had living wills
- 2002 – Means to a Better End – 15-20% had advance directives
- 2005 –Pew Research Center – 29% had living wills
- 2008 – AARP Survey – less than 40% had advance directives; individuals 35+ years of age

Even fewer Americans have had open, honest conversations regarding end-of-life care wishes, a vital component to the advance care planning process.

The MOLST Program is designed to improve the quality of care people receive at the end of life and is based on effective communication of patient wishes, documentation of medical orders on a brightly colored form and a promise by health care professionals to honor these wishes.

165 Court Street Rochester, NY 14647 phone: 585.238.4514 fax: 585.453.6365
Patricia.Bomba@lifethc.com

Excellus

Patricia A. Bomba, M.D., F.A.C.P.
Vice President and Medical Director, Geriatrics

Effective communication between the patient or legally designated decision-maker and health care professionals ensures decisions are sound and based on the patient's understanding of their medical condition, their prognosis, the benefits and burdens of the life-sustaining treatment and their personal goals for care.

MOLST started as a grassroots effort in Rochester as part of the Initiative; workgroup members included consumers. Our work began with research for a model that would ensure patient wishes would be honored and focused on the POLST Paradigm Program with a decade of research and positive results.

It has been my privilege to spearhead collaborative work with the New York State Department of Health on health policy and legislative advocacy for the MOLST Program that has established MOLST as a statewide program. Significant changes in Public Health Law have transformed the scope of practice of EMS in New York State.

Enclosed is a one page addendum that outlines five recommendations for consideration. I look forward to working with you, your staff and others who are committed to improve the quality of care individuals receive at the end-of-life.

Sincerely yours,

Patricia A. Bomba MD

Patricia A. Bomba, M.D., F.A.C.P.
Leader, Community-wide End-of-Life/Palliative Care Initiative

Chair, Monroe & Onondaga Counties Medical Orders for Life-Sustaining Treatment (MOLST) Community Implementation Team and New York Statewide Implementation Team

New York State Representative, National Physician Orders for Life-Sustaining Treatment (POLST) Task Force

165 Court Street Rochester, NY 14647 phone: 585.238.4514 fax: 585.453.6365
Patricia.Bomba@lifethc.com

Compassion and Support
at the End of Life
www.CompassionandSupport.org

MOLST
MEDICAL ORDERS FOR
LIFE-SUSTAINING TREATMENT

Senate Special Committee on Aging

Senator Sheldon Whitehouse, Chair

"Honoring Final Wishes: How to Respect Americans' Choices at the End of Life"

September 24, 2008

10:30 a.m.

Dirksen Senate Office Building, Room 562

Testimony

Addendum

September 28, 2008

Patricia A. Bomba, M.D., F.A.C.P.
Vice President & Medical Director, Geriatrics
Excellus BlueCross BlueShield
Leader, Community-Wide End-of-life/Palliative Care Initiative
Chair, Monroe & Onondaga Counties Medical Orders for Life-Sustaining Treatment (MOLST)
Community Implementation Team and New York Statewide Implementation Team
New York State Representative, National Physician Orders for Life-Sustaining Treatment (POLST) Task Force

POLST

MOLST
A POLST Paradigm Program

Recommendations for considerations:

1. Avoid CMS cuts to hospice reimbursement rates and avoid issuing regulations that impose an undue regulatory burden on the American people. Hospice provides high quality care to patients and their families as noted by my recent personal and longstanding professional experience.

2. Adopt National Quality Forum (NQF) preferred practices on advance care planning from A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report::
    a. #32 Surrogate/Decisionmaker Designation
    b. #33 Patient/Surrogate Preferences
    c. #34 Medical Orders (e.g. POLST Paradigm Program)
    d. #35 Advance Directives Availability
    e. #36 Advance Care Planning Promotion (e.g. Respecting Choices and Community

3. Adopt the POLST Paradigm Program nationally; this is consistent with NQF Preferred Practice #34

4. Expand the HITSP Summary Documents using HL7 Continuity of Care Document (CCD) Component section on Advance Directives Data Mapping to include distinct mapping for both traditional advance directives and "actionable medical orders" that are generated as a result of the POLST Paradigm Programs.

5. Incentivize the conversation that provides for informed medical decision-making that focuses on patient goals, values and beliefs that in turn drive choice of medical interventions.

    a. We currently incentivize action and interventions and not planning utilizing thoughtful discussions.
    b. The interpretation of Medicare regulations must recognize families in current American society are often scattered across the country. Thus, all conversation cannot be face-to-face.
    c. Currently Medicare does not reimburse for non face to face contact (99358, 99359). In Pediatrics face time with the parents is considered equivalent to the patient, in geriatrics the same idea should apply when dealing with a patient with dementia or any patient who lacks capacity to make health care decisions. This would include conversations with surrogate decision makers.

Statement of Richard Grimes, President and CEO, Assisted Living Federation of America

Honoring Final Wishes: How to Respect America's Choices at the End of Life

Written Testimony submitted to the Senate Special Committee on Aging
September 24, 2008

Mr. Chairman,

My name is Richard Grimes, the President and CEO of the Assisted Living Federation of America (www.alfa.org). Thank you for giving us the opportunity to submit testimony on honoring final wishes and respecting individual choices at the end of life.

Nothing is more fundamental than an American's right to decide where and how to live. For some aging Americans, the choices can become conscribed because of frailty, ill health and finances. But poll after poll, study after study, and the personal testimony of thousands of seniors tell us that virtually all want to avoid institutions and remain in home and community settings as they age.

Honoring this choice to remain in a residential setting with privacy, dignity and respect is a core principle of the Assisted Living Federation of America and the professionally managed assisted living communities we serve. The residents of assisted living are frail seniors who need some assistance with the activities of daily living and no longer wish or are able to live in the family home. More than one million residents live in 36,000 assisted living communities in the United States. They do not need 'round the clock nursing care. They get the support they need to dress, bathe or take medication in a setting designed to offer an enriching lifestyle with social and physical activities, great dining and many other services. This philosophy of care embraces choice and independence.

This bedrock principle of choice and independence extends to seniors facing their final days. Americans are living longer and growing older. The average age of an assisted living resident has jumped to 84 for men and 85 for women. Thanks to the supportive services offered in assisted living communities and the tremendous advances in pharmacology, a clear majority of these seniors choose to stay in their assisted living homes until the end of their lives. They want to die as they lived, surrounded by friends and a caring staff and comforted by the familiar. In response to this consumer wish, hospice care is fast becoming a standard offering by our member assisted living communities.

Assisted Living Federation of America members embrace hospice providers because they also focus on providing care in the home instead of an institution. Last year ALFA collaborated with the National Hospice and Palliative Care Association to develop hospice tool kits for our members. These tool kits serve as a guide for our members to help residents with terminal conditions and their families make informed choices. Our members work closely with the residents and their families to help them understand and choose the appropriate treatment options. Their decisions are respected and honored. The goal is to ensure a high quality of life for residents even as they near the end of life. Our members work in partnership with hospice providers throughout the nation to make certain that our terminal residents die a comfortable, dignified and natural death surrounded by those who care.

For many years, nursing homes were the only long term care option for many Americans. Although assisted living has become a viable residential alternative for many seniors in the past 30 years as well as the fastest growing long term option in the United States, the laws and regulations of some states prohibit hospice care in assisted living. These same states allow individuals to avail themselves of hospice care in a private home, a nursing home or a hospital. ALFA worked with its members in Tennessee to change an outdated law and is working with its members to change restrictive laws in other states to reflect the choices and lifestyles of older Americans in 2008.

It is not hard to appreciate the important role this service has played at a painful, sad and deeply difficult time for many seniors and their families. Getting appropriate end-of-life care in a familiar environment without having to go into a hospital has allowed many terminal residents to slip gently into that good night. We thank Senator Whitehouse and the Committee for recognizing the essential humanity and kindness of respecting the choices of each American at the end of life.

The Assisted Living Federation of America is the largest national association serving companies operating professionally managed assisted living communities for seniors. ALFA is the voice for senior living and advocates for informed choice, quality care and accessibility for all Americans needing assistance with long term care. For more information visit www.alfa.org.

Statement

Of

Barbara Lee, PA, FNP, JD

President, Compassion and Choices

Testimony

For the

Special Committee on Aging

Of the

United States Senate

On

Honoring Final Wishes: How to Respect American's Choices at the End of Life

September 24, 2008

Thank you for the opportunity to offer written testimony for your consideration following the September 24th hearing entitled, *Honoring Final Wishes: How to Respect Americans' Choices at the End of Life*. My name is Barbara Lee, and I currently serve as the President of Compassion & Choices (C&C), the oldest and largest organization in the country dedicated to ensuring that Americans have access to a full range of end-of-life care options, including palliative care, improved pain care, hospice care, respect for advance directives, and legal aid-in-dying. We have more than 25 years of experience in advocacy and service. Much of our work is accomplished through the grassroots efforts of our more than 35,000 members and countless volunteers who generously give their time to support and strengthen their communities through direct service to terminally-ill patients and their families. C&C also works with policy makers on the local, state, and federal levels to ensure that the law facilitates an environment where patients are fully informed of all their end of life care options and are empowered to make their own decisions about their end of life care, in consultation with family and medical providers.

Since its inception, C&C has focused its resources on arming patients and their families with the tools to effectively and openly discuss all of the medical options available to them at the end of life. For the last twenty years, we have educated our membership and the general public about the imperatives of planning for the end of life while still mentally competent and in good health. There are countless examples of families who have grappled with tough decisions about how and when to let a loved one die. These families struggle with extremely difficult questions: Should we take grandma off of the respirator? Should our father, who is terminally ill, have an invasive surgery that may only prolong his life for a few more weeks? Will my twenty-seven year old daughter ever regain cognitive function or is she permanently unconscious? Is it time to direct the withdrawal of a ventilator? Will my husband ever awake from an unconscious state? Should we discontinue tube feeding supplying artificial nutrition and hydration? These decisions, even without an immediate need for action are difficult to consider, but they are significantly more difficult in times of a health care crisis. Advance directives help to alleviate some of the stress involved with making decisions about end-of-life care for loved ones. If done correctly, they provide specific directions about desired care and a road map for any situation not explicitly outlined.

At C&C, we believe that every adult needs an advance directive, regardless of age or health. No one can predict the future, and of course, none of us knows when or if an unfortunate event might occur and leave us unable to speak for ourselves. The case of Terri Schiavo offered one of the most extreme illustrations of this fact. I, like millions of Americans, watched with a heavy heart as family members, politicians, interest groups, and the courts grappled with this issue. I was appalled when Congress unnecessarily and inappropriately intruded into what should have been a very private decision made by Terri Schiavo's husband, as her legal surrogate, and her physicians. Regrettably, Terri Schiavo was the rule not the exception. Fewer than 30% of Americans have completed advance directives, and some studies put the number as low as 18%. The numbers for acutely and terminally ill Americans are only slightly better at under than 50%.

During the Schiavo case, C&C responded to more than 26,000 requests for information about advance directives and resources about end-of-life care concerns, but that is just a drop in the bucket compared to the need. What we learned from that experience is that Americans are hungry for tools to assist them with developing advance directives and information about what medical options are available to them at the end of life. As several of the witnesses noted, advance directives are overwhelmingly under utilized, in part because people are not educated about their utility or about the components necessary to make them most useful. We know from our work that many people complete advance directives too hastily, without knowing about or considering all options and without describing fully their wishes for end-of-life treatment. Regrettably, some interested in developing comprehensive advance directives fail to get full and accurate information from their health care providers because the provider refuses to *even inform* patients of options they consider morally objectionable. The notion that a health care provider has a right to refuse to provide information or care that he or she finds morally or religiously objectionable puts the provider's interest ahead of the patient's. This is not professional and should not be permissible. Providers who are unwilling to inform about or provide care to which they object must, at a minimum refer a patient to a provider willing to inform and provide care the patient may want and need. In the end-of-life care context, institutions and individuals opposed to withdrawing feeding tubes, providing aggressive pain care, providing support to a patient choosing to voluntarily stop eating and drinking, or to providing palliative sedation could claim these are 'morally controversial' and thus refuse to inform patients about these options, and not even refer the patient to a provider willing to provide counseling about and access to these interventions.

This is particularly worrisome for patients at the end of life who are often unaware of their options, hesitant to initiate conversations with their providers about certain options, and often unable to remove themselves from their current health care setting in order to seek treatment elsewhere. When dying patients are suffering in the final stages of terminal illnesses, they should be able to receive counseling on a full range of options. This thereby empowers them to make fully informed medical care decisions.

In response, C & C developed materials to address these concerns. We dedicated a full issue of *Compassion & Choices Magazine, Summer 2005* (attached) to the issue of advance directives; and we developed a tool kit which includes detailed instructions, state-specific advance directive forms, and a comprehensive checklist of medical care options. The Advance Directive Tool Kit (attached) is available at no cost on the C&C website. We also saw a need to improve state laws to mitigate the detrimental impact of refusal clauses and importantly, to ensure that patients have full access to information about their legal and medically available end- of-life care options. To that end, C&C worked closely with allies in the California state legislature to craft and pass the Right to Know End of Life Options Act (AB2747). Signed into law by California Governor Arnold Schwarzenegger on September 30, 2008, the Right to Know Act provides terminally ill patients with the opportunity to receive counseling on all end-of-life care options accepted in law and medicine in California. When requested, information about hospice care, refusal or withdrawal of life prolonging treatments, palliative care and palliative sedation would be discussed with the patient. The act also requires that health care providers who do not wish to comply ***must*** refer or transfer that patient to another provider.

While we have expended significant resources toward educating our membership and the general public about the need for advance directives, we know that the federal government could do so much more. The first federal law that deals specifically with advance directives is the Patient Self Determination Act (PSDA). The PSDA, enacted in 1991, requires hospitals, nursing homes, hospice programs, home health agencies, and HMO's to give adults, at the time of inpatient admission or enrollment, information about their rights under state laws governing advance directives, including: (1) the right to participate in and direct their own health care decisions; (2) the right to accept or refuse medical or surgical treatment; (3) the right to prepare an advance directive; and (4) information on the provider's policies that govern the utilization of these rights. Passage of the PSDA was an important first step for creating a uniform mechanism for providing information about advance directives to patients, but it is imperative that Congress do more.

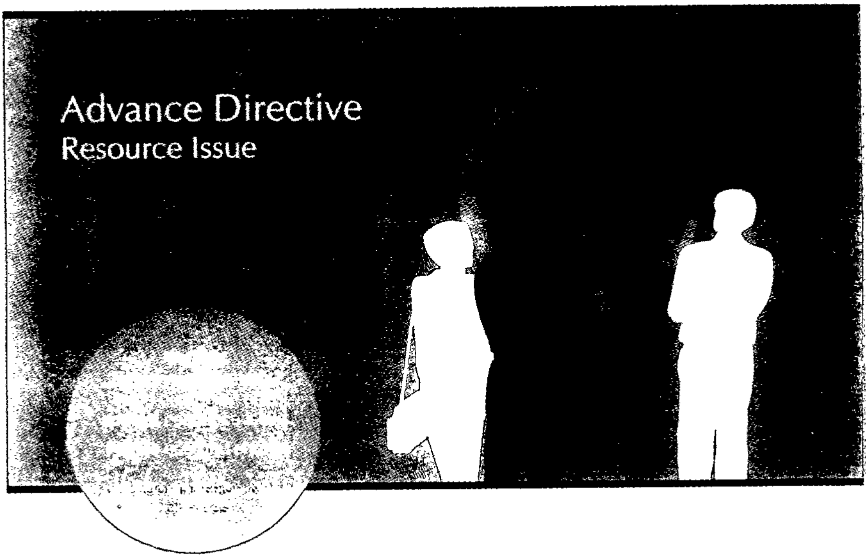
We recommend that Congress:

- Launch a national public education campaign, including a toll-free number and website providing state-specific information on advance directives.
- Create pilot programs and incentives for states to create driver's license designation programs, allowing individuals to indicate on their state issued driver's license that they have executed an advance directive.
- Create a readily accessible database of completed advance directives to ensure that the medical wishes of individuals are available to health care providers nationwide.
- Ensure an advance directive executed in one state is recognized and honored in another state.

Thank you for the opportunity to submit written testimony for the committee's review. We look forward to working with you and your colleagues to pass legislation and promote programs that improve the quality of end-of-life care for all Americans.

Compassion and Choices

MAGAZINE
Summer 2005



Advance Directive
Resource Issue

[illegible] YOUR WISHES [illegible] IMPROVING LAWS [illegible]

Compassion and Choices

MAGAZINE

Summer 2005 Volume 4 Number 2

Advance Directive Resource Issue

INSIDE:

www.compassionandchoices.org

From Your CEOs

Barbara Coombs Lee

Welcome to the second issue of the *Compassion and Choices Magazine*. The subject of advance directives and end-of-life decisions has been in the headlines often over the past year. In light of this attention, we are devoting this entire issue to a discussion of end-of-life planning as a resource to you as you complete your advance directive, or as you review and revise it. Your advance directive can provide not only the means to express your wishes, it also serves as a tool to begin meaningful discussions with those you care about and those who will care for you.

Every adult needs an advance directive for health care. Regardless of age, regardless of health, none of us knows when a future event might leave us unable to speak for ourselves. If you were not able to make or communicate decisions about medical treatment, a written record of your health care wishes would prove invaluable.

We understand that for some, filling out an advance directive can be daunting and we hope this will make it easier. It is an important step to ensuring your choices are honored. Without these documents it will become more and more difficult to exercise your choices.

As millions of Americans watched coverage of the Schiavo case earlier this spring, Compassion & Choices responded to more than 26,000 requests for advance directives and other information about end-of-life concerns. While it was disheartening to watch the family members, the courts and even our government grapple with this issue, one positive outcome was the increased awareness that every adult American, regardless of age, must take steps to ensure their wishes are followed.

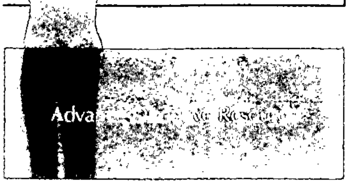
Besides raising awareness, the Schiavo case also brought a strong reaction from social conservatives who are working harder than ever to impede our hard-won victories for choice at the end of life. As the opposition takes aim at end-of-life choice, the growing threat to our rights is just now becoming clear. Not only do they not want us to expand choice at the end of life, but they want to take away the rights we already have.

If they prevail and these changes become law, it will have a major impact on the right to choose a peaceful, timely death in a case of permanent unconsciousness. Compassion & Choices is on the offensive in the battle to protect our rights, and will keep you apprised in our publications and on our Web site.

In the meantime, please feel free to contact us with any questions. We are your resource, and we can help you navigate through the legal and medical maze and make sure your wishes are honored.

Now more than ever, we must be vigilant in protecting existing laws, diligent in learning about the opposition, and outspoken in supporting choice.

Basics
What's an Advance Directive?



ADVANCE DIRECTIVE
(ADVANCE DIRECTIVE FOR HEALTH CARE)

Advance directive is a generic term for documents that typically include a living will and durable power of attorney for health care. These documents allow you to provide instructions relating to your future health care, such as when you wish to receive treatment or when you wish to stop or refuse life-sustaining treatments.

The part often referred to as the *living will* is a place for you to specify what kinds of treatments and care you would or would not want if you were unable to speak for yourself.

The other part, often called a *durable power of attorney for health care* allows you to appoint someone to act on your behalf in matters concerning your health care when you are not able to decide for yourself due to illness or incapacitation. This document covers health issues only; it does not include finances, estate or business concerns. The person you appoint might be called your health care agent, proxy or representative. This publication uses the term agent.

Together these documents are commonly referred to as your *advance directive*. Research shows that the term *living will* is more widely recognized than *advance directive* by Americans. For this reason *living will* is used on the Compassion & Choices Web site to describe our services. Ⓒ

Decisions
How to Make Your Health Care

WHAT ARE YOUR WISHES?

Beginning the process of creating an advance directive can seem daunting. What should go in it? How detailed should it be? There are so many scenarios to consider that it can be overwhelming. Rather than trying to think of everything that could happen, focus on specific situations. Begin by asking yourself some questions and write down your thoughts about each.

- Are there basic functions you believe you *must have* in order to feel that you would want to continue to live? Do you feel you must be able to recognize loved ones or to respond to others?
- Do your spiritual or religious beliefs affect your attitudes about a terminal illness, treatment decisions, or death and dying? Do you believe life-sustaining treatments should never be withheld or withdrawn? Or do you believe that when there is no hope of recovery, death should be allowed?
- Are there specific kinds of life-sustaining treatment you *would want* to have if you were diagnosed with a terminal condition? If you could not eat or drink, would you want a feeding tube?
- Are there specific life-sustaining treatments you would *not want* to have if you were diagnosed with a terminal condition?
- Is there a particular doctor you want to help your family make decisions about your care?
- Is there anyone you *do not want* involved in your

health care decisions? Example: specific family members, friends, or professionals

If given a choice, where would you prefer to die?

(Adapted from documents produced by Oregon State University)

Many states' living will forms mention at least two scenarios, permanent unconsciousness and terminal illness. They make it easy for you to state whether or not you would want continued life support under those circumstances. Some forms mention two or three more prototypical scenes. You can cross out and initial any of the scenarios you don't wish to include in your choice to accept or reject life support.

In addition to the choices on the forms, it's important to include your considerations in making your choice. In an increasing number of states, the law presumes you would want to be fed and hydrated artificially, unless you have a written instruction that specifically rejects this treatment and overrides the presumption. Also keep in mind that you will be fed as long you have the ability to chew and swallow, even if you have lost all cognitive abilities. If such a situation is a concern, you might want to refuse spoon feeding in your living will.

Your living will is very helpful to your physician, family, and your health care agent when they must make choices on your behalf. It is important to understand that these documents alone do not guarantee enforcement. The more you can do to prevent conflicting opinions about your wishes, the greater the likelihood those wishes will be followed.

For more information on the decisions you can make see section *Your Wishes* on page 11.

WHO WILL YOU APPOINT?

In your durable power of attorney for health care, you appoint a health care agent to carry out your wishes. This legal document gives the person you appoint the right to direct your health care if you are unable to make or communicate decisions. Your agent can be anyone you choose who is at least 18 years of age—your next of kin or another family member, or someone outside the family.

To prevent conflicts of interest, avoid choosing your primary care physician or any other health care practitioner involved in your care. Many states will prohibit you from doing this, unless the practitioner is related to you by blood, marriage or adoption.

You will also want to name an alternative agent, and cover

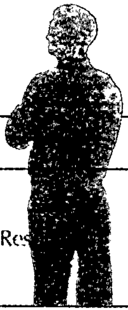
Continued on Page 8

At a glance

- A living will records your health care instructions. You describe what medical care and treatments you do or do not want to receive.
- A durable power of attorney for health care allows you to name a person to direct your health care when you cannot do so. Choose someone who will follow your instructions and insist that your end-of-life wishes be respected.
- Together these documents make up your advance directive. Some states combine them in one form.
- It is not enough just to have a living will and durable power of attorney for health care. Discuss your choices with your doctor and your family.
- Your doctor should be willing to honor your advance directives or refer you to one who will.

Living Will + Durable Power of Attorney
= Advance Directive

Glossary



Advance Directive Re

Important terms for a more thorough

Coma A coma is a profound or deep state of unconsciousness. The patient is alive, yet is not able to react or respond to the environment.

CPR Abbreviation for cardiopulmonary resuscitation, an emergency procedure often employed after cardiac or respiratory arrest, in which cardiac massage, artificial respiration, and drugs are used to maintain the circulation of oxygenated blood to the brain.

DNR Abbreviation for a Do-Not-Resuscitate order. A DNR is a specific physician order that alerts medical staff of your desire not to be resuscitated in the event that your heart stops beating (cardiac arrest) or you stop breathing (respiratory arrest).

Palliative Care Also referred to as comfort care or hospice care. An active, compassionate approach to the care of the dying that emphasizes pain relief and comfort rather than curing or prolonging life. The goal is to achieve the best quality of life possible by relieving suffering and controlling pain and symptoms.

Persistent Vegetative State Refers to a condition in which an individual has lost all cognitive function and awareness of the environment, but retains noncognitive function, including some sleep-wake cycles. A patient in this condition is still able to breathe and may exhibit various spontaneous movements.

POLST Abbreviation for a Physician Order for Life-Sustaining Treatment. The POLST form is a brightly colored, one-page form your physician can use to turn your wishes into specific written medical orders. Your physician may use the POLST to write orders that reflect the types of life-sustaining treatment, such as CPR or tube-feeding, or focus on comfort that you do or do not want and that are appropriate for your medical situation. It is not an advance directive, but rather a means to translate an advance directive into physician orders to be followed by all medical personnel. Currently, only about one-third of all states have POLST forms available. Make sure to check with your physician, as more states are introducing them.

Total Sedation Also referred to as palliative or terminal sedation. The continuous administration of medication to relieve severe, intractable symptoms that cannot be controlled while keeping the patient conscious. This treatment renders the patient unconscious and relieves suffering by inducing an artificial coma. The unconscious state is maintained until death occurs.

Ventilator A ventilator is a mechanical device that supplies air to the lungs when natural breathing is impaired.

understanding of the
issues related to decision-making.

Voluntary Stopping of Eating or Drinking This means voluntarily refusing food and liquids, with the understanding that this will result in death. If food and fluids are taken through a stomach tube, the decision would be to stop this treatment. Contrary to popular belief, the patient does not starve to death. Rather, death usually results from dehydration. It is important to note that hunger and thirst diminish and the desire for food becomes practically non-existent as death nears.

Withholding, Refusal or Withdrawal of Treatment An ethically and legally accepted practice that may be specified in advance directives. You always have the right, as a mentally competent adult, to refuse, or discontinue any treatment or procedure such as ventilator support, kidney dialysis, cardiac pacemaker or an other intervention.

Enforcing Advance Directives

Do you know of a case where advance directives were not honored by a health care facility? Contact Bryanne Jones at 800.247.7421 or by email at bjones@compassionandchoices.org

Myth and Fact

Myth: **You always have to use your state's statutory form for your advance directive to be valid.**

Fact: Many states do not require a particular form, but require witnessing or other specific signing formalities. Other states specify a particular form. Contact Compassion & Choices for your state's correct forms.

Myth: **Advance directives are legally binding, so doctors have to follow them.**

Fact: Advance directive laws give doctors and others immunity if they follow your valid advance directive. A more reliable strategy is to discuss your values and wishes with your health care providers ahead of time, to make sure they understand what you would want and are willing to support your wishes.

Myth: **An advance directive means "do not treat."**

Fact: An advance directive can express ***both*** what you want and don't want.

Myth: **If I name a health care agent, I give up the right to make my own decisions.**

Fact: Naming a health care agent does not take away any of your authority. You always have the right while you are still competent to make your own health care decisions or revoke a directive.

Myth: **Once I give my doctor a signed copy of my directive, my task is done.**

Fact: Advance care planning is an ongoing process. Review your wishes annually or anytime your health or family status changes. Make the appropriate changes. Communicate those changes as needed and give copies of revised documents to those who need them.

Myth: **You must have a living will to stop treatment near the end of life.**

Fact: Treatment may be stopped without a living will if everyone involved agrees. However, without some kind of advance directive, decisions may be more difficult and disputes more likely.

Myth: **Advance directives are only for old people.**

Fact: It is true that, on average, older people are more likely to have advance directives, but every adult should have one. Some of the best-known choice-in-dying cases arose from the experiences of young people (e.g. Terri Schiavo, Nancy Cruzan, Karen Ann Quinlan) incapacitated by tragic illness or car accidents and maintained on life support.

Adapted from documents produced by the American Bar Association

C&C

***Decisions**, continued from Page 5*

the same questions with that person. The alternative agent will step in if your first choice is unavailable or otherwise unable to act. If you have designated a spouse and subsequently are divorced, many states will not recognize that person as a legitimate health care representative.

Remember, your health care agent(s) can make your decisions only if you are incapable of doing so. For example, your health care agent might make decisions while you are unconscious, but once you are conscious again, you will make your own decisions.

As you consider potential agents, ask yourself, "Are they assertive? Do they live nearby? Are they comfortable talking about death? Will they respect my values?"

In any case, your family should know and understand how you have instructed your agent and whom you have appointed as your agent. Whatever you say, make sure to explain things in detail. ***Many people complete advance directives too hastily, without considering all options and without describing fully their wishes for end-of-life treatment.***

During these conversations, tell your agent just what you think about "extreme measures" doctors might use to prolong your life. Do you want every treatment available, no matter how limited the benefit might be? Or would you rather forego treatment once it becomes clear that death is inevitable?

There may be instances when a person has no one appropriate to serve as their agent. If this is your situation, please contact our Client Support Program at 800.247.7421. We may be able to suggest some resources to assist you. There are still effective means of expressing your wishes.

WHAT SHOULD YOU DO NEXT?

Experience tells us that advance directives, when easily accessible, carefully prepared and appropriately communicated, can go a long way toward making sure you get the type of care you want.

Talking to family members about your wishes is the single most important step in this process. A frequent problem is disagreement among loved ones. If physicians hear of such disagreement, they could be justified in continuing life-sustaining treatment, to avoid a possible lawsuit or licensing complaint.

Conversations with loved ones about your wishes and feelings about end-of-life care can be difficult, but there are sensitive ways to broach the conversation. If you can have this conversation when all or most of your loved ones are gathered together it will help ensure a common understanding of your wishes. You might begin the discussions with:

"I want to make sure that I get the best care possible and the type of care that I want, so there are things we should talk about..."

"Since none of us knows what the future will bring, there are some things that I think we should all talk about..."

"If you are ever in a position where you need to make health care decisions for me, it will be most helpful to you if you know what I really want..."

Unlike speaking to your family about your wishes, making your advance directive accessible is an easy thing to do. Give copies to your agent, your alternative agent and your doctor.

It is very important to find a doctor whom you trust and who will take the time to listen to you and your family. Consider the following when discussing your advance directive with your physician.

Make an appointment to discuss your wishes.

Bring your agent with you to this appointment.

Tell them what matters to you most.

If you are concerned about suffering, talk to them about your concerns. ©

Voices

Do No Harm

My son, Bob, was the chief of the emergency room at our local community hospital. He was a beautiful human being, a wonderful caring doctor and a fantastic athlete. In high school in Los Angeles, he was a first-string All City quarterback. He was scouted by two professional baseball teams for his pitching ability, had many football scholarships offered before finally accepting a scholarship to Stanford.

After deciding that medicine was his true love, he went on to become one of the youngest board-certified emergency room specialists in the country. His way of relaxing, after a full shift at the hospital, was to do a 10-mile run and then lift weights. It was there, in the mirror, lifting weights, that he saw the signs of what proved to be breast cancer.

The medicine he received from the excellent and concerned palliative care team was not enough for him, and actually had the effect of making him paranoid and constipated. The treatment of the latter made him incontinent. The hospice image of the family gathered around as the patient dies in comfort was unachievable. He lived in agony, his dignity gone.

Greater doses of pain medication left him comatose. With a lesser dose, he was in agony. He withdrew from his kids, nephews, friends and parents. Bob's persona was gone. His cancer, and his pain-riddled body, remained.

I ask of those who oppose aid-in-dying, who would have been harmed if my son had died two weeks earlier? Could he have been made more comfortable if there had been no fear of the legal barriers to the use of pain medications?

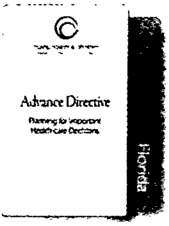
I urge you, for your own sake, for the sake of your parents and for the sake of your own children, pass this humane law. Pass AB 651.

—Eugene Glick

About the author: Eugene Glick is a member of Compassion & Choices. He shared the story of his son, Bob, as an impassioned plea to the California legislature to pass the Compassionate Choices Act.

Send original *Voices* contributions to: Editor, Compassion & Choices, P.O. Box 101810, Denver, CO 80250 or email editor@compassionandchoices.org

The Toolkit



Compassion & Choices is your resource for advance directive documents.

The Toolkit Includes:

- State-specific Advance Directives
- The Dementia Provision
- My Particular Wishes
- Helpful instructions for filling out these forms.

To download the Advance Directive Toolkit for free, please visit us online. You may also call us at 800.247.7421 to have your Advance Directive Toolkit mailed for a postage and handling fee of $5.

Who. What. Where.

Already Have Your Toolkit?

You have taken the first step, answering the WHAT. You still need to make sure you have spoken to your agent and loved ones about you wishes, WHO. The final step is the WHERE. Make sure copies of your advance directive are in the right places: your agent, your home or obvious place for your agent or loved one to find it, and your doctor.

Making a Difference

by Carissa Snyder

Alberta Golden in Seattle

After four years of conducting advance directives training in the Seattle area, Alberta Golden knows what the documents are worth. "Peace of mind," she declares. "That's the legacy you leave to your family."

As a Compassion & Choices of Washington affiliate board member and active volunteer, Alberta's trainings are not her only contribution to choice at the end of life, but they are unique. Rather than brief seminars, they are intense, four-hour workshops, usually held over a two-day period. Classes are limited to no more than a dozen attendees, so participants have the opportunity to talk and interact. Her trainings are offered in various locations as needed, including senior centers, local meetings, and in a seniors' course at a local community college.

The workshops focus on the core elements of effective advance directives. Rather than simply filling out forms, participants consider the difficult questions posed by advance health care decisions: Whom should you choose as a health care surrogate? What should you say when you talk to your doctor? What should you say to your family? To answer these questions, many participants have to dig deep into their desires and motivations, discovering just what they would like the end of life to be like, and whom they trust to help them achieve it.

> choices at the end of life. I'm giving them the opportunity to exercise them."
>
> Alberta Golden, a board member of Compassion & Choices of Washington, discussing her advance directive training.

Alberta participated in her first advance directives training at a meeting of a women's group of which she is a member. More than 30 people split into three smaller groups, and Alberta facilitated one of the groups. At the end of the session, 33 women had completed their advance directives for health care.

After seeing the tangible difference the event made, Alberta was hooked. "When 10 people leave the workshop with their affairs in order, I've made a difference," she says. Word began to spread, and Alberta began to receive requests. Her training program was launched.

One of the things Alberta highlights in her training is how important it is to keep a complete file of your advance directive and related paperwork, called a "Last Wishes File". And don't file it away! "Put it somewhere available, and make sure other people know about it," she advises. The idea is that convenience and availability are key.

The facilitated discussion is arguably the most valuable portion of the extended workshop. "At least half the people who come already have their forms," Alberta points out. "They want to learn more," she says.

Alberta, who will soon turn 74, doesn't plan to bring in her shingle anytime soon. For now, she is pleased to continue helping people find ways to enforce their health care wishes. "People already have choices at the end of life. I'm giving them the opportunity to exercise them," she says. "This stage of my life is a gift to me." ℂ

Your Wishes
Deciding About Life Support

There is no question that western medicine has made amazing advances in recent decades, but for people whose illness cannot be cured, this medical progress presents a modern dilemma. Only you can decide how much treatment is enough, where the line is between therapeutic and futile treatment, and the most difficult decision for many—how long your life should be prolonged after it has ceased to be "life" as you define it. These questions don't have any easy answers.

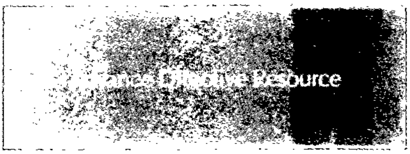
This section provides information about the options you should have in deciding which medical interventions can be used when biological functions cannot maintain themselves. These are commonly called "life support" and are also known in the medical world as "life-sustaining measures."

These terms usually refer to medications to stimulate heart function, artificial food and water, or artificial ventilation. People who are terminally ill often do not want such interventions, which would only prolong their dying process. Others must consider what they would want in the case of sudden cardiac arrest or traumatic brain injury; debating what would be best for them and for their loved ones.

Usually interventions are stopped because the patient recovers or because the treatment is not achieving the desired goal.

Withholding and Withdrawal of Treatment

Life support is considered "withheld" when the patient or the patient's health care agent instructs health care providers not to begin a medical therapy, and the expected result is that the patient will die without it. This option is often selected by patients who are already terminally ill and in the dying process. Life support is considered "withdrawn" when a therapy that has been initiated is stopped. Often, the patient or patient's agent, other loved ones, and the attending physician, agree on a time-limited trial of life-support therapy, hoping for improvement. If the patient does not improve, the therapy is stopped.



While you can always direct your own medical care if you are conscious and capable, this can change if you are incapacitated. Some state laws require you to record in writing your wish to have life support withheld. In these states, life support is always initiated *unless* you have written documents requesting otherwise, and even your designated agent cannot change this.

If you want life support to be withheld or withdrawn after a certain period, it is imperative that you complete a living will and durable power of attorney for health care. A doctor's order may also serve this purpose. See DNR below.

Artificial Ventilation

Artificial ventilation is often used while treating the underlying problem that causes the patient to be unable to breathe. A tube is inserted through the mouth into the windpipe, and a machine pushes a precise combination of oxygen and air into the lungs, at a controlled speed and pressure. Sometimes the tube is inserted into the windpipe (trachea) through a hole made in the throat. Also called mechanical

Continued on Page 12

A Poem by a Member

Never Ever
by [redacted]

Carol Stevens w[redacted]passion & Choices. After Carol d[redacted]her daughter, who is also a member, found t[redacted]poem on her desk.

Never ever will I watch the sea again
The waves rushing and crashing
Against the rocks
To be pulled back again by the restless tide.

Never ever will I see the mountains again
Covered by green pines and golden aspen
The peaks touched by last year's snow.
Which trickles downward in crystal clear streams.

***Your Wishes**, continued from Page 10*

ventilation, artificial ventilation brings oxygen and air to the lungs of a person who cannot breathe on their own.

Some patients are given artificial ventilation, and are then slowly weaned off it. But many patients are unlikely to recover the ability to breathe alone. The longer a patient uses artificial ventilation, the less likely recovery becomes.

DNR ORDER AS A TOOL

A DNR order instructs health care providers not to attempt to resuscitate you if your heart stops. This option is sometimes selected by people who, for medical reasons, would not benefit from CPR. Discuss with your doctor whether a DNR is appropriate for you.

Some states allow you to include DNR instructions in your living will. If yours does not, you will need to complete a separate document. Also keep in mind that instructions in your living will may not apply if you receive emergency care, such as in the event of a sudden collapse. If you do not want resuscitation attempted in any circumstance, you need a DNR form that is separate from your living will, sometimes called a "non-hospital" DNR. In most states this form requires a physician's signature.

Paramedics are usually required to initiate rescue and resuscitation measures. If you have a DNR order, it is important to display it prominently. Prepare family members and neighbors in case they should find you without heartbeat and not breathing.

Non-hospital DNR orders can be difficult to enforce. Emergency personnel rarely withhold resuscitation and they are not required to search for DNR documentation in an emergency. If you want to reject all emergency efforts, you must persuade your family and neighbors, far ahead of time, not to call 911 if they should find you without signs of breathing or heartbeat. To learn about local practices and ask what you need to do to enable paramedics to comply with your DNR, call your local ambulance service or fire department.

ARTIFICIAL FOOD AND WATER

An adult may forego or terminate active treatment such as chemotherapy, radiation therapy, antibiotics,

- Your advance directive is key to making your wishes known if you should be unable to communicate.
- Death shouldn't have to include fear, pain or suffering, and planning is one of the best ways to avoid it.
- Create your living will now.

Never ever will I follow the rugged road
That went I knew not where
Over the unknown hill and around the next sharp curve.
Looking back to the road I'd just traveled.

Never ever will I hear the shrill cry of a golden eagle again
As it dives earthward for its prey
Spreading those gorgeous wings with the rushing wind
Against the backdrop of the evening sky.

Only in memory will I catch the glimpse
Of a sudden smile on that dear loved face.
Or feel the touch of a warm embrace
Of hands that soothed and caressed.

Only in memory can I see it all again
Memories of those times and places
Memories I can never lose or replace
I know they are there hidden deep
In the recesses of my mind.
And I am content.

or other medications. Similarly, the choice of whether to take food or water, by mouth or through a tube, is the patient's. But if you have situations in which you do not wish to receive this treatment, you need to record your wishes in your living will. Some states require you to receive artificial nutrition and hydration unless you have stated otherwise in writing.

Nutrition and hydration are provided for patients who cannot swallow, cannot swallow sufficient amounts, or cannot absorb nutrition through the stomach. In the case of a person who cannot swallow, this can be provided through a tube. This can be a nasogastric tube, a tube that is inserted through the nose, or a percutaneous endoscopic gastrotomy (PEG) tube, a tube that is surgically inserted directly into the stomach. If you are terminally ill and do not wish to be fed artificially, you can still receive artificial hydration, usually through an intravenous tube.

YOUR WISHES

Your life support preferences should be recorded in your living will, and discussed with your health care agent, doctors, family and loved ones. Be sure you have all the information you need, and make your decisions carefully. Discuss these situations with your primary physician, and take your general health and other health conditions into account.

Did You Know?

Your membership card from Compassion & Choices has space on the back for the name and phone number of your agent(s) for health care. As a benefit of membership at the Benefactor level and above, Compassion & Choices can put your advance directive on a wallet size CD rom that you can carry with you. To learn more about this level of membership, call us 800.247.7421.

Are you a life member of Compassion & Choices?

If not call us at 800.247.7421 to find out how you can avoid annual membership renewal.

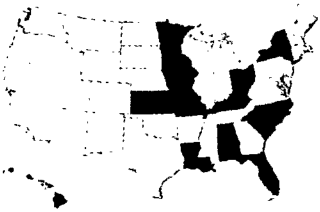
As part of your advance directive, we recommend including two supplements developed by Compassion & Choices: "My Particular Wishes" and "The Dementia Provision," which are available through Compassion & Choices. If you have additional questions as you determine, record and communicate your wishes, please contact our Client Support Program at 800.247.7421. Our staff counselors can provide individual information and support as you complete your documents.

Michelle Holbrook
Director of Legislative Affairs

Kathryn Tucker, JD
Director of Legal Affairs

Many legislative sessions are over for the year, but our efforts to improve laws that affect choice and care at the end of life never stop! The summer months include significant projects at Compassion & Choices.

Pending Bills to Restrict Health Care Decisions



Want to help fight health care decision restrictions in your state? Contact us at 800.247.7421 or visit our online legislative action network at www.compassionandhoices.org

As always, we owe many thanks to our dedicated members, supporters and volunteers who work at the grassroots level to support our legal and legislative efforts. Without your hard work and dedication, none of these changes would be possible.

Our legal team is gearing up for the next round in the fight to preserve Oregon's aid-in-dying law. The U.S. Supreme Court will consider the Justice Department's appeal this fall. The high court will determine whether the federal Controlled Substances Act, designed to prohibit interstate trafficking of narcotics, can be used by the Justice Department to prosecute doctors who prescribe medication under the Oregon law.

A U.S. District Court and the Ninth Circuit Court of Appeals already struck down the Justice Department's efforts, and this appeal is their last chance to nullify Oregon's law. Compassion & Choices, with generous participation by the law firm, Heller Ehrman White & McAuliffe, serves as co-counsel to a group of terminally ill Oregonians who want the law to be available to them. These people join the state of Oregon and an Oregon physician in fighting this appeal.

Many readers will recall that the Supreme Court's decision in *Washington v. Glucksberg*, a case brought by Compassion In Dying in the 1990s, invited states to grapple with the issue of aid in dying, exactly as Oregon has done. We hope the court will recall this invitation, issued only eight years ago, and rebuff the Justice Department's efforts to prevent states from addressing this issue.

But our work isn't all at the federal level. We're leading the fight to advance legislation in several states, particularly California, New York and Vermont.

California's AB 651, the Compassionate Choices Act, would give the state an aid-in-dying law much like Oregon's. After passing through two committees in the Assembly, the bill is now under consideration in the Senate. We hope to see this bill safely to the governor's desk.

Every day counts! If you're a voter in California, we urge you to contact your assembly member and senator. Every phone call, every letter and every postcard truly makes a difference. If you don't live in California, but you know people who do, please ask them to take action by calling their elected officials.

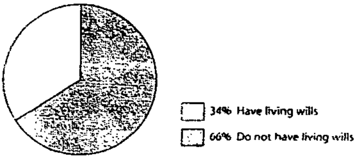
In Vermont, we continue to support proponents of H.

Improving Laws

168 which is similar to California's AB 651, while in New York, we're supporting several bills to improve pain and palliative care.

Compassion & Choices is also carefully monitoring several "health care decision restriction" bills. These bills are designed to make a "presumption of life" by requiring clear and convincing evidence to allow the withdrawal of artificial nutrition and hydration from incapacitated patients who are near the end of their life—even if all family members are in agreement about the patient's choice to have life-sustaining measures removed.

These bills are a devastating example of government interference with the practice of medicine. Even more, they illustrate the need for every adult—young or old, ill or in good health—to have their advance directives in order and their health care wishes in writing. See the map to find out if your state has or is considering a health care decision restriction bill.



Public Opinion

A recent Harris Poll showed that 72 percent of Americans would specify "no life support" in a living will if they had one. Still, only 34 percent of Americans actually have a living will, and the majority of those are age 65 and over. To view the complete results of the poll, please visit www.compassionandchoices.org

Ask the Expert

I wrote my living will 10 years ago. Recently I took it out and read it, and I still agree with everything in it. But will the old date be a barrier in a hospital, or heaven forbid, a courtroom?

You want whoever is reading your documents to feel confident that you agree with everything that's in them. If your documents are more than five years old, it's time to renew them. Some states require that your advance directives be less than five years old to be valid. We recommend that you review these documents annually. Under your original signature write "reviewed on (date)" and sign.

We love our New England summers, but every year we winter in Arizona. We vote in Arizona and spend the most time there. Should our advance directives be Arizona documents?

If you spend significant time in more than one state, it's best to complete a living will and durable power of attorney for health care in each state. That way, you can be sure to have the necessary documents for both places of residence.

Do you receive *The Advocacy Bulletin*?

Trying to keep up-to-date on our efforts to improve laws? Make sure you have the latest information at your fingertips!

Subscribe to our free legal and legislative newsletter on our Web site at www.compassionandchoices.org or by calling 800.247.7421

C&C

In the News

France Allows Withdrawal of Treatment

In an initial step to expand choice at the end of life, France has passed a law that allows doctors to remove life support if there is no hope to achieve an improvement in the person's health and if these extend life artificially. For the first time in France, terminally ill patients are able to stop treatment, and families of unconscious patients can request withdrawal of life support.

Pennsylvania Court Upholds Advance Directives

A Pennsylvania county court recently stopped a health care surrogate from enforcing a medical decision that was contrary to the patient's written directives. John King, 72, is an elderly Alzheimer's patient who is permanently unconscious. Though his living will stated that he did not want tube feeding under any circumstances, his wife and legal decision-maker requested a feeding tube. Mr. King's daughter, who is his co-surrogate, has prevailed in the Bucks County Court so far.

Terri Schiavo Postscript

Autopsy results on Terri Schiavo were released by the attending medical examiner on June 15. The findings show that Mrs. Schiavo had irreversible brain damage with no possibility of consciousness, and that she was blind. There were no indications of physical abuse, as well as no proof that Mrs. Schiavo suffered from an eating disorder, as alleged in a 1992 civil trial. The cause of her initial collapse remains unknown.

Mrs. Schiavo's case became known nationwide during a bitter court battle between her husband and her parents over whether she would have wanted to be kept alive artificially. Mrs. Schiavo's tragic and even yet unexplained collapse at age 26 underscores the need for all Americans to create advance directives and make their health care wishes known.

Special Events

Arizona

End-of-Life Choices Flagstaff
September 3, 2005
Flagstaff, Arizona

Bob McMillan, Director of Flagstaff Mortuary, will discuss pre-arranged funeral plans and Gerry Blair, Community Relations with Flagstaff Police Department, will discuss 911 emergency procedures and other topics. For information call Severy Partridge at 928.774.5105 or email Partridgebird2@yahoo.com.

California

Compassion & Choices at the UCLA Hammer Museum
October 5, 2005
Los Angeles, CA

Discussion about the culture of living and dying in America. David Kessler, Barbara Coombs Lee, Paul Spiers and Reverend Frank Wulf will discuss building a culture that acknowledges the primacy of conscience in defining the parameters of choice.

Florida

Lakeland Community Group
July 20, 2005
Lakeland, Florida

Living will and surrogate workshop, led by Mary Grove and Portia Westerfield. For information, reservations or directions, call Mary Grove, 863.680.1234.

New Hampshire

New Hampshire End-of-Life Choices
October 15, 2005 in Portsmith, New Hampshire
October 16, 2005 in Keene, New Hampshire

Paul Spiers, PhD, co-chair of the Compassion & Choices national advocacy center, presents "A Time for Change: The National Debate on End-of-Life Care and Choice."

Speakout: Readers' Comments

Political Football

My heart aches for the husband and parents of Terri Schiavo. My soul is disturbed that politicians have made their distress a political football.

My father lost half his face to cancer—he wouldn't even allow his grandchildren to see him. After surviving the surgery, he caught pneumonia. He lay in his hospital bed, whispering "...ask, ...ask." My mother, brother and I didn't understand, but his caring doctors did. He wanted the mask removed. My father weighed only 68 pounds when he passed away.

I will never, never put my family through this.

My husband and I both belong to Compassion & Choices. Their "Letter to My Physician" has gone with our health care power of attorney to all our doctors and our local hospital. The counselors available at the toll-free number are so helpful.

It should be your decision to live or die—not politicians or the courts.

ALENE DUNCAN

California

22 Years Old

I should have the right to end my life if I am in a vegetative state or if I have cancer and there is no hope for me.

My niece just passed away; she was 22 years old. Her parents had her removed from life support because she had told them she didn't want to live like that—because it isn't living. They simply did as she had wished.

ANONYMOUS

Illinois

Dehumanized

I wish Compassion & Choices would stop using the term "persistent vegetative state." I've had loved ones who were described by that term, and I found it very insulting. As brain damaged as they were, they certainly were not like vegetables. Human beings need not be dehumanized in order to make the case that they should be allowed to die with dignity.

MATTHEW COSTELLO

Indiana

Editor's Response—

As an organization that values dignity, choice and control at the end of life, we agree with your distaste for the term. Choice at the end of life allows us to remain ourselves until the end, and we would never wish to denigrate seriously injured patients. However, the term "persistent vegetative state" is a medical one. When recording your health care wishes, it is beneficial to use the same terms that doctors use, to help make sure your wishes are understood and honored. For this reason, we use and define this term in this magazine.

Not Too Late for Me

My dear, 83-year-old husband, deep into Parkinson's and dementia, was admitted to the hospital with seizures and an unidentified infection. He has wanted to die for a couple of years.

He was identified as having a "swallowing problem," and was given thickened liquids and pureed foods. Now he can't even handle thin liquids, and survives bent over, on a sugar drip—which I will now have stopped. He can hardly bear to look at me.

It's too late for him, but maybe it's not too late for me.

PAT GLADIS

Pennsylvania

Organization News

Sweet Success at Big Apple Gala

Movement leaders joined New York movers and shakers for the second Compassion & Choices of New York benefit reception on May 19th at the studio of world famous fashionista Diane von Furstenberg. The art auction featured pieces by artists Claes Oldenburg, Maira Kalman, Christo and Jeanne-Claude, and the late Roy Lichtenstein.

The combination cocktail party, art auction and reception honored journalists and writers for their contributions to raising public awareness and dialogue about choice and care at the end of life. The evening brought more than 300 people together and raised more than $120,000 for Compassion & Choices of New York.

At the event, Robb Miller, executive director of Compassion & Choices of Washington, received the 2005 Hugh Gallagher Award. This award was created through the generosity of Peter Kovler to commemorate the significant contributions of Hugh Gallagher, who used his writing to educate the public about injustices, to promote understanding among diverse populations and to draw people into the choice-in-dying movement.

Robb represents the best of Compassion & Choices. He is passionate, innovative and courageous in reaching out to diverse groups to educate and advocate for exceptional end-of-life-care that respects the beliefs and values of all individuals. As executive director of our Washington affiliate, Robb has engaged numerous coalitions and organizations in order to advance the quality of end-of-life care. With the support of the Pride Foundation, Robb created the GLBTQ End-of-Life Advice & Hospital Visitation Form (available at www.compassionandchoices.org).

New Board Member

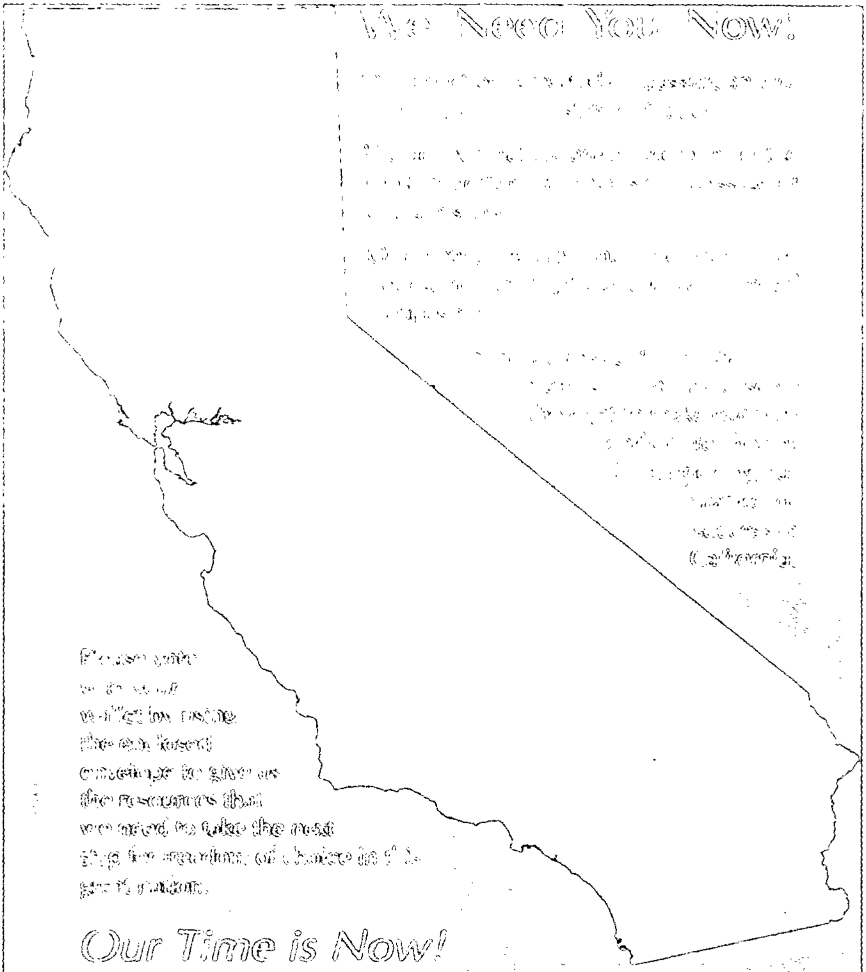
A new member of the Compassion & Choices national board, Megan Roach is president of Roach Consulting, LLC, an independent consulting business specializing in health care and strategic management consulting. Megan has more than 20 years of experience in the health care industry and in consulting, focusing on strategic planning, product development, marketing, operations, and state and federal regulatory compliance. Megan has been a board member of the Minnesota chapter of Compassion & Choices since the spring of 2004. Megan brings her knowledge and expertise to help us identify and implement strategic plans and legislative initiatives that will strengthen our organization.

New Staff

Join us in welcoming new members to our national team. Mark Ferguson and Bryanne Jones join our staff in Portland. Mark, a social worker by trade, has years of experience working with the terminally ill and bereavement including pet loss. Bryanne has recently completed a master's degree in bioethics from Case Western University. John Franzgrote, a former news photographer, is a strong believer in compassion and is also a pet lover. Before coming to Compassion & Choices, Jennifer Rue had been working at the Downtown Denver Partnership. She is committed to nonprofit organizations, changing laws and helping others. She and John join our staff in Denver.

New Web site

Compassion & Choices' new Web site is up and running at www.compassionandchoices.org. Use this online resource to find out more about more about client support, our legal and legislative services, and more.



We Need You Now!

[illegible]

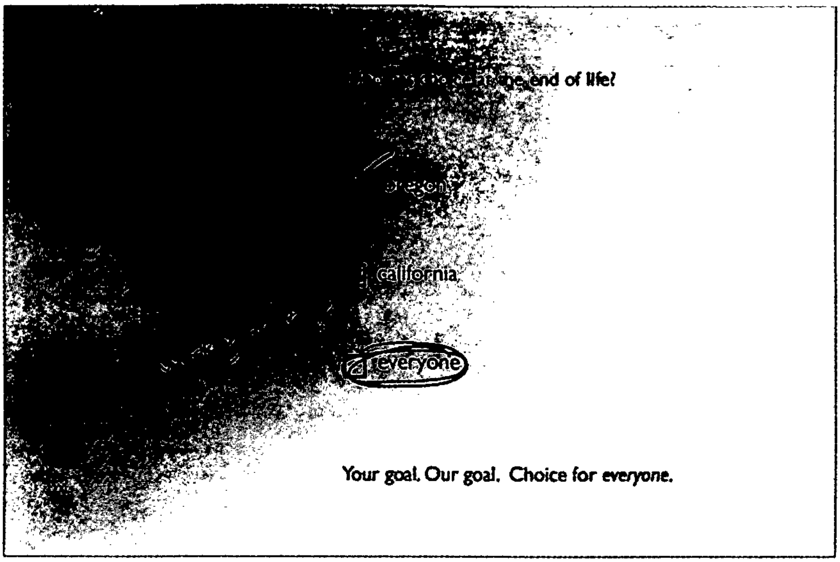
[illegible]

[illegible]

[illegible] California.

Please help
[illegible]
[illegible] by using
the enclosed
envelope to give us
the resources that
we need to take the next
step for freedom of choice in this
generation.

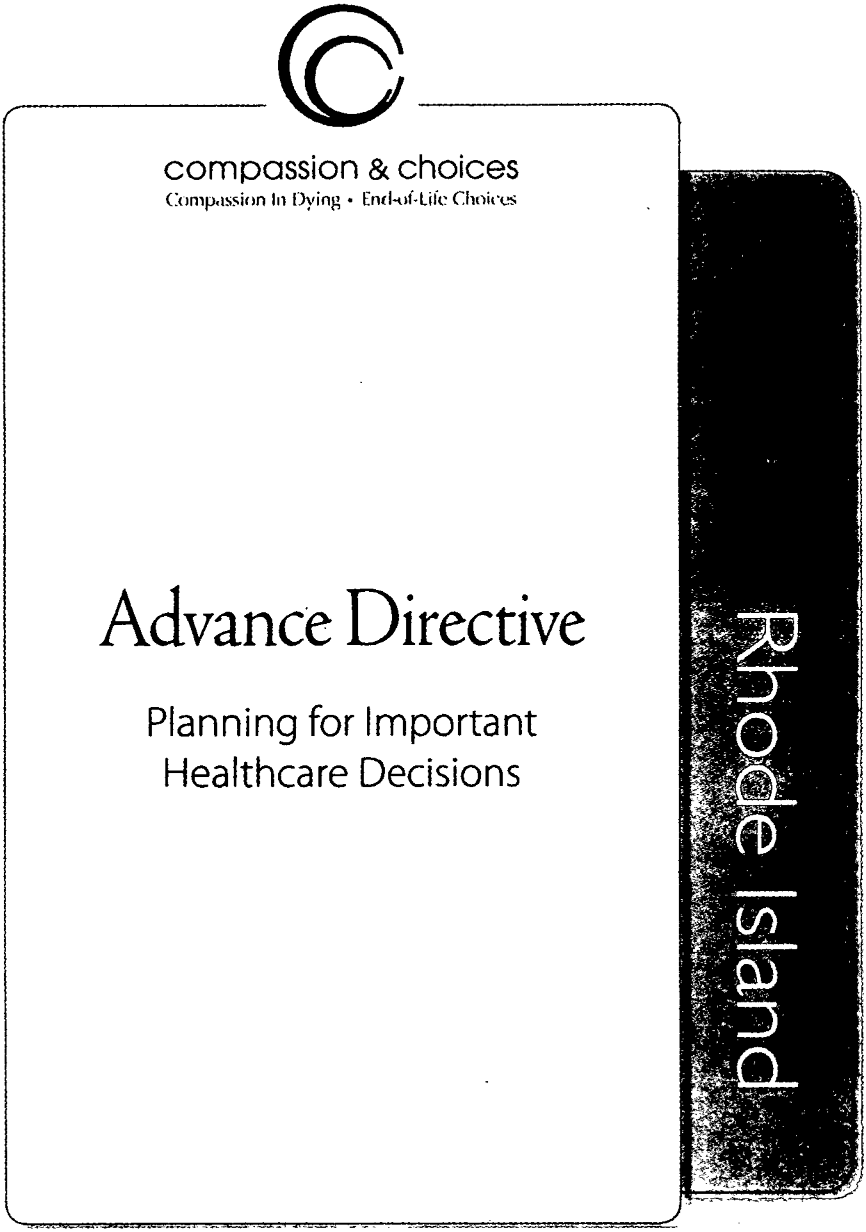
Our Time is Now!



compassion & choices
Compassion In Dying • End-of-Life Choices

P. O. Box 101810 • Denver, Colorado 80250-1810

Periodicals



compassion & choices
Compassion In Dying • End-of-Life Choices

Advance Directive

Planning for Important Healthcare Decisions

Rhode Island

compassion & choices
Compassion In Dying • End-of-Life Choices

Congratulations on taking the first step in protecting your right to freedom and choice at the end of life. These documents will help ensure that you continue to make your own health care decisions. They offer not only personal autonomy – they also give you and your loved ones peace of mind, knowing that your wishes are firm and clear.

We'll be here when you need us! Providing advance directive documents is just one of the many services we offer. Compassion & Choices members receive, free of charge, counseling and guidance on how to complete and how to use advance directives. Those who join at the Benefactor level or above can receive a wallet-sized CD of their advance directives, which they can carry with them at all times. Emergency personnel will find this CD tucked in with your health insurance card and it will speak for you when you cannot speak for yourself. Please contact us to learn more about this service!

Your dues and donations to Compassion & Choices assure the continuation of our programs and services. Our Client Support Program is unsurpassed in offering comprehensive service and support for individuals and families as they contemplate life's end. Our education program provides literature and speakers in communities across the nation. And our advocacy team defends your right to a peaceful death on legal and legislative fronts.

Join today to enlist Compassion & Choices as your lifelong advocate! Count on us to help you protect yourself from government intrusion into health care, and to protect your family from disputes over your end-of-life care. Through our national team of volunteers and top-notch legal talent, we stand ready to deliver advocacy services by telephone, at the bedside, and even in the courtroom, if necessary.

Please join us in our effort to ensure care, choice, dignity and control at life's end!

✂--

☐ **Yes! I want to join Compassion & Choices** (make your check payable to End-of-Life Choices)

☐ Individual ($45)	☐ Couple/Dual ($60)	☐ Benefactor ($100)
☐ Individual Life ($450)	☐ Couple/Dual Life ($600)	

☐ I choose not to join now, but please accept my enclosed donation of
☐ $50 ☐ $100 ☐ $150 ☐ $_____ (make your check payable to Compassion & Choices)

Credit card number: ______________________________ Expiration: __________

☐ Visa ☐ Mastercard

☐ I cannot contribute right now, but please keep me on your mailing list.

Name: ____

Address: ____

City, State, Zip: ____________________________________

Daytime phone: ___________ Evening phone: ___________ Email: ______________

www.compassionandchoices.org

P.O. Box 101810
Denver, CO 80250

tel 800.247.7421
fax 303.639.1224

compassion & choices
Compassion In Dying • End-of-Life Choices

HOW TO USE THESE MATERIALS

1. Check to be sure that you have the materials for your state. You should complete a form for the state in which you expect to receive healthcare.
2. These materials include:
   - Instructions for preparing your advance directive
   - Your state-specific advance directive forms.
3. Read the instructions in their entirety. They give you specific information about the requirements in your state.
4. You may want to photocopy these forms before you start so you will have a clean copy if you need to start over.
5. Talk with your family, friends, and physicians about your decision to complete an advance directive. Be sure the person you appoint to make decisions on your behalf understands your wishes.

If you have questions or need guidance in preparing your advance directive or about what you should do with it after you have completed it, you may call our toll free number (800) 247-7421 and a staff member will be glad to assist you.

P. O. Box 101810, Denver, CO 80250-1810
tel 800.247.7421 fax 303.639.1224
www.compassionandchoices.org

Introduction to your Rhode Island Advance Directive for Health Care

Every adult needs an advance directive for health care. Regardless of age, regardless of health, none of us knows when a future event might leave us unable to speak for ourselves. If you were not able to make or communicate decisions about your medical treatment, a written record of your health care wishes would prove invaluable.

What is an Advance Directive for Health Care?

Advance directive is a generic term used for documents that traditionally include a living will and the appointment of a health care agent. These documents allow you to provide instructions relating to your future health care, such as when you wish to receive medical treatment or when you wish to stop or refuse life-sustaining medical treatments.

The living will portion of an advance directive is a place for you to specify what kinds of treatment and care you would or would not want if you were unable to speak for yourself. The living will is also called the Rhode Island Declaration. The second part, often referred to as the Durable Power of Attorney for Health Care, allows you to appoint someone to act on your behalf in matters concerning your health care when you are unable to speak for yourself due to illness or incapacitation. Please note that the person you appoint to speak on your behalf may be called your health care agent, proxy, or representative.

Why is it useful?

Whereas traditional living wills are limited to cases of terminal illness, health care advance directives are not. Rather, they help you to maintain control over health care decisions that are important to you when you are unable to make or communicate decisions due to temporary or permanent injury or illness. An advance directive for health care allows you to express your wishes about any aspect of your health care, including decisions about life-sustaining treatment. It also allows you to choose a person to speak on your behalf and communicate your decisions when you are not able to do so. Appointing an agent and making sure your agent is aware of and understands your wishes is one of the most important things you can do. If the time comes for a decision to be made, your agent can participate in relevant discussions, weighing the pros and cons of treatment decisions based upon your wishes. Your agent can make health care decisions on your behalf whenever you cannot do so for yourself, even if your decision-making capacity is only temporarily affected. If you choose not to appoint an agent, many health care providers and institutions will make decisions for you. As they tend to err on the side of prolonging life, their decisions may not be based on your wishes. In some cases, if you do not have an advance directive, a court may have to appoint a guardian. Another important consideration is your family. Advance directives help relieve the stress and duress associated with having to make important health care decisions on behalf of someone you care about. By making your wishes known in advance, you help your family and friends, who may otherwise struggle to decide on their own, know what you would want done.

Are Advance Directives for Health Care legally valid in every state?

Yes, advance directives are legally valid in every state. Each state and the District of Columbia have laws that permit individuals to sign documents stating their wishes about health care decisions when they cannot speak for themselves. The specifics of these laws vary, but the basic principle of listening to the patient's wishes is the same everywhere. The law gives great weight to any form of written directive. If the courts become involved, they usually try to follow the patient's stated values and preferences, especially if they are in written form. An advance directive for health care may be the most convincing evidence of your wishes you can create. It is important to note that while it is legal to have an advance directive in every state, no current law requires that they be strictly honored by health care professionals.

What does an Advance Directive for Health Care say?

There are two parts to this advance directive for health care. The first, and most important, portion allows you to appoint someone (your agent) to make health care decisions on your behalf, should you be unable to decide for yourself. You can define the degree of authority (how much or how little) you want your agent to have. Also, you can name those you wish to be your alternate agents, should your primary agent be unwilling or unable to act on your behalf. Additionally, you can state individuals you do not want to make decisions for you.

If there is no one whom you trust to serve as your agent, then you should not name an agent. The second part of the advance directive can be used as a guideline for your heath care providers. If this is your case, contact Compassion & Choices at 800-247-7421 for help with finding an agent.

In the second part of the advance directive, you specify your health care treatment wishes. Remember, you can include treatments and procedures you *do or do not* want. You can also include statements regarding organ and tissue donation. The instructions you provide in this portion of the form provides evidence of your wishes. Your agent and anyone providing you with medical care should follow them. Although you are not required to complete either or both parts of an advance directive, Compassion & Choices encourages you to do both.

How do I make an Advance Directive for Health Care?

The procedure for creating an advance directive for health care varies, depending on where you live. Most states have laws that provide specific forms and signing procedures. Most states also have witnessing requirements and restrictions on who you can appoint as your agent (such as prohibiting your physician from being your appointed agent). Make sure to follow these rules closely. Most states require two witnesses and many either require or allow a notarized signature. Some even have special witnessing requirements if you reside in a care facility (nursing home, assisted living facility, etc.). Even if witnesses are not required, we encourage you to consider using them anyway. Doing so reinforces the deliberate nature of your act and may help increase the likelihood that health care providers in other states will honor the document. If you use the attached form, you should be able to meet most states' advance directive requirements.

In Rhode Island, the person you appoint to serve as your health care agent *can not be your treating health care provider, an employee of your treating health care provider who is not related to you, the operator of a community health care facility, or the employee of an operator of a community health care facility who is not related to you.* Rhode Island law requires that you sign your advance directive in the presence of two witnesses, who must also sign your advance directive. This is done to show that they know you and believe you to be of sound mind. Your witnesses *can not* be any of the following: *your health care agent, any alternate health care agents you may appoint, a health care provider, an employee of a health care provider, the operator of a community health care facility, or the employee of an operator of a community health care facility.* At this time, you are not required to have your Rhode Island advance directive notarized.

If I change my mind, can I change or cancel my Advance Directive for Health Care?

Yes, you can change or cancel your advance directive at any time. You can do this by notifying your agent and/or health care provider in writing of your decision to do so. It is best to destroy all copies of your old advance directive and create a new one. Make sure to provide copies of your new form to the appropriate individuals. Compassion & Choices recommends that you review your advance directive every year and re-sign and date it to indicate that this document continues to reflect your wishes.

Before you begin: What do I need to consider before completing my Advance Directive for Health Care?

What are my goals for medical treatment?

When thinking about goals of medical treatment, it is important to consider two main conditions, an extended period of disability and terminal illness. While it is impossible to anticipate all of the different situations that could arise, you can make your wishes known by clearly stating your treatment goals. Consider what you want medical treatments to accomplish. Do you want treatments to prolong your life, regardless of it's quality? Or would you prefer to stop (or not start) life-sustaining treatments if your consciousness and ability to communicate could not be restored? By stating your medical treatment goals, you help your family and health care provider make decisions on your behalf. If a particular treatment would help achieve one of your goals, it would be provided. But if it would not help achieve a treatment goal, it would not be provided.

In creating your treatment goals, it is helpful to consider how you feel about a particular treatment after you decide what your wishes are. For example, if you do not want to be kept alive on a ventilator (a machine that helps you breathe), why don't you want this? Do you not like that it inhibits your mobility or independence? Or is there another factor? Would it make any difference if you needed a ventilator for only a few days as opposed to many months? Answers to these types of questions reflect what you value and will shape your medical treatment goals. To help you in determining these goals, you may wish to complete the Values Statement found on the following two pages and consider the following questions:

How do you feel about your current health?

How important is independence and self-sufficiency?

How to you envision handling disability, illness, dying, and death?

How might your personal relationships affect medical decision-making near the end of life? Is there anyone you do not want involved in your health care decisions (e.g., specific family members, friends, or professionals)?

What role should physicians and other health care providers play in your medical decision-making processes? Is there a particular doctor you want to help your family make decisions about your care?

If you become seriously ill or disabled, what type of living environment is important to you?

Are there any financial aspects you wish to be considered during any decision-making process?

What are your general thoughts on life and its end – hopes, fears, joys, sorrows?

Are there basic functions you believe you must have in order to feel that you would want to continue to live? Do you feel you must be able to recognize loved ones and respond to others?

Do your spiritual or religious beliefs affect your attitudes about a terminal illness, treatment decisions, or death and dying? Do you believe life-sustaining treatments should never be withheld or withdrawn? Or do you believe that when there is no hope of recovery, death should be allowed?

Are there specific life-sustaining treatments you would want to have if you were diagnosed with a terminal condition? If you could not eat or drink, would you want a feeding tube?

Values Statement to accompany Advance Directive:

When I am dying, the following are important to me (e.g., physical comfort, pain management, family, friends, or pets present, special objects I want near, etc.): ______________________

I do not want the following around me when I am dying: (e.g., particular people, things, places I do not want to be, etc.): ______________________

In the case of a terminal illness, permanent coma, or irreversible chronic disease (such as Alzheimer's disease), I feel that life-sustaining treatments should: ______________________

I would like the following financial aspects to be considered when treatment decisions are being made (such as expenses not to exceed health insurance coverage, self-pay, etc.): ______________________

Additional thoughts on death and dying (place of death – die at home, hospital, etc., burial, cremation, funeral, memorial service, etc.): ______________________

Not everyone that participates in my end-of-life health care will agree with the values and choices that are involved in my decision-making processes. However, the above values are thoughtfully held by me and represent what I feel is important as I near my death. They reflect the choices and decisions I want made on my behalf if and when I am unable to speak and decide for myself.

______________________ ______________________

Signature Date

	1 = Not Important 5 = Very Important				
I want to know the truth about my condition.	1	2	3	4	5
I want to take part in decision-making involving my health care.	1	2	3	4	5
I want my health care agent to participate in my health care decision-making if I am unable to decide for myself.	1	2	3	4	5
Letting nature "take its course".	1	2	3	4	5
Maintaining my quality of life.	1	2	3	4	5
Maintaining my dignity.	1	2	3	4	5
Maintaining my privacy.	1	2	3	4	5
Living as long as possible, regardless of quality of life.	1	2	3	4	5
Having physical mobility.	1	2	3	4	5
Having good eyesight.	1	2	3	4	5
Having good hearing.	1	2	3	4	5
Having reasonable mental capacity.	1	2	3	4	5
Being able to speak.	1	2	3	4	5
Being able to communicate with others nonverbally – writing, touch, blinking, etc.	1	2	3	4	5
Having independence and control in my life.	1	2	3	4	5
Avoiding being a burden on others.	1	2	3	4	5
Being comfortable and pain-free, even if it may hasten my death.	1	2	3	4	5
Leaving good memories for friends and family.	1	2	3	4	5
Leaving assets for family, friends, charities, etc.	1	2	3	4	5
Dying in a short while, as opposed to a lingering process.	1	2	3	4	5
Financial aspects.	1	2	3	4	5

Other thoughts and feelings regarding medical treatments: ______________________________

____

____

____

____

____

____

____

____

Signature Date

Who should be my agent?

One of the most important things you can do is to appoint an agent to speak for you if and when you are ever unable to do so for yourself. An agent has great power over your health care and should be carefully chosen. In normal circumstances, no one will be monitoring your agent and their decisions.

To help avoid disagreements, we recommend selecting one primary agent and at least one alternate agent. Your alternate agent would speak on your behalf if your primary agent were unwilling or unable to speak for you. Your agent must agree to serve this role. It might be important to mention that your health care agent bears no financial burden or liability if they agree.

Before deciding on an agent (and alternatives), ask yourself: "*Are they assertive? Will they be able to make difficult and possibly emotional decisions? Do they live nearby? Are they comfortable talking about death? Will they respect my values and wishes?*" Then, talk to them. Share your wishes and make sure they clearly understand what is important to you. Confirm their willingness to speak on your behalf.

If you can not think of anyone you trust to serve as your agent, do not appoint anyone. Make sure to complete the living will portion of the advance directive to express your wishes. This will act as a guideline for your treating physicians. If this is your situation, contact Compassion & Choices at 800-247-7421 for help in locating an agent.

Can I include personal instructions? If so, how specific should I be?

If you have any preferences or specific wishes, it is important to put them down on paper and to discuss them with your agent and health care providers. Since it would be nearly impossible to predict every situation you may face, note those that are important to you. Consider ventilator support, artificial nutrition and hydration, kidney dialysis, and the use of antibiotics. You may feel differently about enduring a treatment for a few weeks as opposed to several months or years; it is important to note such things. Use statements such as, "If I am terminally ill and nearing the end of my life, I do not want to be put on a ventilator if doing so would only prolong my life," instead of, "I never want to be put on a ventilator." The purpose of an advance directive is to provide guidance. Express your beliefs and be as specific as you are comfortable being.

How can I make sure health care providers will follow my advance directive?

Currently, there are no state laws that oblige medical personnel to honor your advance directive. Some health care providers have values and opinions that do not agree with the wishes you have expressed. Because of this, they may not want to follow the directions you provide in your advance directive. Most state laws allow doctors to refuse to honor your advance directive on conscience grounds. However, they must help you find another physician willing to honor your wishes. While this is rare, it is important to be aware of its potential.

To help avoid this situation, talk to your health care providers ahead of time. Make sure they understand your wishes and are familiar with your advance directive documents. And make sure they are willing to honor them. If they object, work out the issues or find another health care provider.

Once your advance directive is completed and signed, provide your agent, all health care providers, close friends and relatives, and anyone else who may be involved with your care with a copy.

What happens if I do not have an Advance Directive for Health Care?

If you do not have a health care advance directive and you are unable to make health care decisions for yourself, some state laws allow surrogates, default decision-makers, to make treatment decisions on your behalf. Typically, surrogates are family members (by order of kinship). Some states authorize close friends to make medical decisions for you, but usually only in rare instances when family are not available.

Even without such statutes, many physicians and health care facilities routinely consult family, as long as close family members are available and do not disagree. Be aware that problems can arise if family members do not know what a patient would want in a given situation. There is also the potential for disagreement regarding the best course of action to take. Disagreement can easily undermine family consent. If this is the case, a physician or other specialist who does not know you well may become your decision-maker. In rare instances, a court may become involved in order to resolve disagreements. In these situations, decisions regarding your health care may not reflect your wishes. And decisions may be made by individuals you would not want doing so. If left without guidance, your family and friends may suffer needless agony in making life-and death decisions on your behalf. We recommend appointing a health care agent and making your wishes known by completing an advance directive.

Who can help me create my Advance Directive for Health Care?

You do not need a lawyer to create your health care advance directive. A lawyer may be helpful if your family situation is complex or if you expect problems to arise. Compassion & Choices recommends you start by talking to someone you trust, who knows you well, and who you feel can help you to state your values and wishes.

Your primary health care providers are important participants to include in the creation of your advance directive. Based on your medical history and your current health, discuss the types of medical problems you may face. Your provider can help you to better understand potential treatment options. Make sure your provider clearly understands your treatment wishes and goals.

Compassion & Choices provides up-to-date state-specific information about advance directives. Take the time to consider what is important to you and seek advice so that your advance directive reflects your beliefs. If you would like help completing your advance directive for health care, contact Compassion & Choices at 800-247-7421.

After you have completed your forms:

What do I do once I have completed my Advance Directive for Health Care?

Once you have completed your advance directive, review it with your agent and any alternate agents you may have appointed. We recommend doing this to make sure those that may have to act on your behalf clearly understand what your wishes are. Completing the advance directive form is not enough. Conversations with agents, family, and health care providers are critical.

Next, you want to make photocopies of your original signed documents. Provide copies to your agent, alternate agent, close family and friends, health care providers, clergy, and anyone else you feel may become involved in your health care or would like to share it with. When distributing these copies, make sure to review your wishes and expectations with them.

While you can keep a copy of your advance directive in a safe deposit box, the original should not be stored there. Rather, keep your documents in an accessible place and let others know where they are, in case they are ever needed.

And remember, you can change or revoke your advance directive at any time.

Other important information:

It is important to note that your advance directive may not be honored in the event of an emergency, such as when someone calls 911. Emergency medical personnel are legally obligated to treat you and require a separate order that states not to do so. These orders are commonly called "out-of-hospital do-not-resuscitate orders (DNR)," "out-of-hospital DNRs," and "non-hospital DNRs." In addition to these forms, some states allow Physician Order for Life-Sustaining Treatment (POLST) forms. In these forms, a physician is able to turn your wishes into specific written medical orders that reflect your medical situation. This is a form signed by your physician and is usually provided to those with a terminal prognosis or illness. Currently not all states have laws authorizing non-hospital DNRs and POLSTs. If you would like further information on this, call Compassion & Choices at 800-247-7421.

Rhode Island Statuatory Form Durable Power of Attorney for Healthcare

WARNING TO PERSON EXECUTING THIS DOCUMENT

(R.I. Gen. Laws 23-4.10-1 to 23-4.10-2 [1989])

This is an important legal document which is authorized by the general laws of this state Before executing this document, you should know these important facts:

You must be at least eighteen (18) years of age and a resident of the state of Rhode Island for this document to be legally valid and binding. .

This document gives the person you designate as your agent (the attorney in fact) the power to make healthcare decisions for you. Your agent must act consistently with your desires as stated in this document or otherwise made known.

Except as you otherwise specify in this document, this document gives your agent the power to consent to your doctor not giving treatment or stopping treatment necessary to keep you alive.

Notwithstanding this document, you have the right to make medical and other healthcare decisions for yourself so long as you can give informed consent with respect to the particular decision. In addition, no treatment may be given to you over your objection at the time, and healthcare necessary to keep you alive may not be stopped or withheld if you object at the time.

This document gives your agent authority to consent, to refuse to consent, or to withdraw consent to any care, treatment, service, or procedure to maintain, diagnose, or treat a physical or mental condition. This power is subject to any statement of your desires and any limitation that you include in this document. You may state in this document any types of treatment that you do not desire. In addition, a court can take away the power of your agent to make healthcare decisions for you if your agent:

(1) Authorizes anything that is illegal,
(2) Acts contrary to your known desires, or
(3) Where your desires are not known, does anything that is clearly contrary to your best interests.

Unless you specify a specific period, this power will exist until you revoke it. Your agent's power and authority ceases upon your death except to inform your next of kin of your desire to be an organ and tissue donor.

You have the right to revoke the authority of your agent by notifying your agent or your treating doctor, hospital, or other healthcare provider orally or in writing of the revocation.

Your agent has the right to examine your medical records and to consent to their disclosure unless you limit this right in this document.

This document revokes any prior durable power of attorney for healthcare.

You should carefully read and follow the witnessing procedure described at the end of this form. This document will not be valid unless you comply with the witnessing procedure.

If there is anything in this document that you do not understand, you should ask a lawyer to explain it to you.

Your agent may need this document immediately in case of an emergency that requires a decision concerning your healthcare. Either keep this document where it is immediately available to your agent and alternate agents or give each of them an executed copy of this document. You may also want to give your doctor an executed copy of this document.

(Continued)

RHODE ISLAND STATUTORY FORM
DURABLE POWER OF ATTORNEY FOR HEALTHCARE

1. DESIGNATION OF HEALTHCARE AGENT.

I, ____,
(name)

____
(address)

do hereby designate and appoint: ________________________________
(name of agent)

____
(address)

____
(home telephone number) (work telephone number)

(insert name, address, and telephone number of one individual only as your agent to make healthcare decisions for you. None of the following may be designated as your agent: (1) your treating healthcare provider, (2) a nonrelative employee of your treating healthcare provider, (3) an operator of a community care facility, or (4) a nonrelative employee of an operator of a community care facility.) as my attorney in fact (agent) to make healthcare decisions for me as authorized in this document. For the purposes of this document, "healthcare decision" means consent, refusal of consent, or withdrawal of consent to any care, treatment, service, or procedure to maintain, diagnose, or treat an individual's physical or mental condition.

2. CREATION OF DURABLE POWER OF ATTORNEY FOR HEALTHCARE. By this document I intend to create a durable power of attorney for healthcare.

3. GENERAL STATEMENT OF AUTHORITY GRANTED. Subject to any limitations in this document, I hereby grant to my agent full power and authority to make healthcare decisions for me to the same extent that I could make such decisions for myself if I had the capacity to do so. In exercising this authority, my agent shall make healthcare decisions that are consistent with my desires as stated in this document or otherwise made known to my agent, including, but not limited to, my desires concerning obtaining or refusing or withdrawing life-prolonging care, treatment, services, and procedures. *(If you want to*

(Continued)

limit the authority of your agent to make healthcare decisions for you, you can state the limitations in paragraph 4 ["Statement of Desires, Special Provisions, and Limitations"] below. You can indicate your desires by including a statement of your desires in the same paragraph.)

4. STATEMENT OF DESIRES, SPECIAL PROVISIONS, AND LIMITATIONS. *(Your agent must make healthcare decisions that are consistent with your known desires. You can, but are not required to, state your desires in the space provided below. You should consider whether you want to include a statement of your desires concerning life-prolonging care, treatment, services, and procedures. You can also include a statement of your desires concerning other matters relating to your healthcare. You can also make your desires known to your agent by discussing your desires with your agent or by some other means. If there are any types of treatment that you do not want to be used, you should state them in the space below. If you want to limit in any other way the authority given your agent by this document, you should state the limits in the space below. If you do not state any limits, your agent will have broad powers to make healthcare decisions for you, except to the extent that there are limits provided by law.)*

In exercising the authority under this durable power of attorney for healthcare, my agent shall act consistently with my desires as stated below and is subject to the special provisions and limitations stated below:

a. Statement of desires concerning life-prolonging care, treatment, services, and procedures:

(Continued)

b. Additional statments of desires, special provisions, and limitations regarding healthcare decisions:

(You may attach additional pages if you need more space to complete your statement. If you attach additional pages, you must date and sign EACH of the additional pages at the same time you date and sign this document.) If you wish to make a gift of any bodily organ you may do so pursuant to the Uniform Anatomical Gift Act.

____ I want to be an organ donor. In the event of my death I request that my agent inform my family/next of kin of my desires to be an organ and tissue donor if possible. My wishes are indicated below.

I wish to give:

____ any needed organs/ tissues: or

____only the following organs/tissues:______________________________

____

5. INSPECTION AND DISCLOSURE OF INFORMATION RELATING TO MY PHYSICAL OR MENTAL HEALTH. Subject to any limitations in this document, my agent has the power and authority to do all of the following:

a. Request, review, and receive any information, verbal or written, regarding my physical or mental health, including, but not limited to, medical and hospital records.

b. Execute on my behalf any releases or other documents that may be required in order to obtain this information.

c. Consent to the disclosure of this information. *(If you want to limit the authority of your agent to receive and disclose information relating to your health, you must state the limitations in paragraph 4 ["Statement of desires, special provisions, and limitations"] above.)*

(Continued)

6. SIGNING DOCUMENTS, WAIVERS, AND RELEASES. Where necessary to implement the healthcare decisions that my agent is authorized by this document to make, my agent has the power and authority to execute on my behalf all of the following:

a. Documents titled or purporting to be a "Refusal to Permit Treatment" and "Leaving Hospital Against Medical Advice."

b. Any necessary waiver or release from liability required by a hospital or physician.

7. DURATION. *(Unless you specify a shorter period in the space below, this power of attorney will exist until it is revoked.)*

This durable power of attorney for healthcare expires on ____________________

(Fill in this space ONLY if you want the authority of your agent to end on a specific date.)

8. DESIGNATION OF ALTERNATE AGENTS. *(You are not required to designate any alternate agents but you may do so. Any alternate agent you designate will be able to make the same healthcare decisions as the agent you designated in paragraph 1, above, in the event that agent is unable or ineligible to act as your agent. If the agent you designated is your spouse, he or she becomes ineligible to act as your agent if your marriage is dissolved.)*

If the person designated as my agent in paragraph 1 is not available or becomes ineligible to act as my agent to make a healthcare decision for me or loses the mental capacity to make healthcare decisions for me, or if I revoke that person's appointment or authority to act as my agent to make healthcare decisions for me, then I designate and appoint the following persons to serve as my agent to make healthcare decisions for me as authorized in this document, such persons to serve in the order listed below:

A. First Alternate Agent: ____

____

(Insert name, address, and telephone number of first alternate agent.)

B. Second Alternate Agent: ____

____

(Insert name, address, and telephone number of second alternate agent.)

9. PRIOR DESIGNATIONS REVOKED. I revoke any prior durable power of attorney for healthcare.

(Continued)

Rhode Island Durable Power of Attorney for Healthcare : Page 6 of 7

DATE AND SIGNATURE OF PRINCIPAL

(YOU MUST DATE AND SIGN THIS POWER OF ATTORNEY)

I sign my name to this Statutory Form Durable Power of Attorney For Healthcare on

______________________________ at ______________________________,
(date) (city)

______________________________.
(state)

____
(you sign here)

(THIS POWER OF ATTORNEY WILL NOT BE VALID UNLESS IT IS SIGNED BY TWO (2) QUALIFIED WITNESSES WHO ARE PRESENT WHEN YOU SIGN OR ACKNOWLEDGE YOUR SIGNATURE. IF YOU HAVE ATTACHED ANY ADDITIONAL PAGES TO THIS FORM, YOU MUST DATE AND SIGN EACH OF THE ADDITIONAL PAGES AT THE SAME TIME YOU DATE AND SIGN THIS POWER OF ATTORNEY.)

STATEMENT OF WITNESSES

(This document must be witnessed by two (2) qualified adult witnesses. None of the following may be used as a witness:

1. A person you designate as your agent or alternate agent,
2. A healthcare provider,
3. An employee of a healthcare provider,
4. The operator of a community care facility,
5. An employee of an operator of a community care facility.

At least one of the witnesses must make the additional declaration set out following the place where the witnesses sign.)

I declare under penalty of perjury that the person who signed or acknowledged this document is personally known to me to be the principal, that the principal signed or acknowledged this durable power of attorney in my presence, that the principal appears to be of sound mind and under no duress, fraud, or undue influence, that I am not the person appointed as attorney in fact by this document, and that I am not a healthcare provider; an employee of a healthcare provider; the operator of a community care facility; nor an employee of an operator of a community care facility.

(Continued)

Signature: ______________________________

Print Name: ______________________________

Residence Address: ______________________________

____

Date: ______________

Signature: ______________________________

Print Name: ______________________________

Residence Address: ______________________________

____

Date: ______________

(AT LEAST ONE OF THE ABOVE WITNESSES MUST ALSO SIGN THE FOLLOWING DECLARATION.)

I further declare under penalty of perjury that I am not related to the principal by blood, marriage, or adoption, and, to the best of my knowledge, I am not entitled to any part of the estate of the principal upon the death of the principal under a will now existing or by operation of law.

Signature: ______________________________

Print Name: ______________________________

Signature: ______________________________

Print Name: ______________________________

Rhode Island Declaration

I, ____,
(name)

being of sound mind, willfully and voluntarily make known my desire that my dying shall not be artificially prolonged under the circumstances set forth below, do hereby declare:

If I should have an incurable or irreversible condition that, without the administration of life-sustaining procedures, will cause my death, and if I am unable to make decisions regarding my medical treatment, I direct my attending physician to withhold or withdraw procedures that merely prolong the dying process and are not necessary to my comfort, or to alleviate pain.

Other directions:

This authorization ( ) **includes** ( ) **does not include** the withholding or withdrawal of artificial feeding. (check only one option)

Signed this ____________ day of ______________________________, 20 ______________.
(date) (month) (year)

Signature ____

Address ____

The declarant is personally known to me and voluntarily signed this document in my presence. I am not related to the declarant by blood or marriage.

Witness ____

Address ____

Witness ____

Address ____

The Dementia Provision

Most Advance Directives become operative only when a person is unable to make health care decisions and is either "permanently unconscious" or "terminally ill." There is usually no provision that applies to the situation in which a person suffers from severe dementia but is neither unconscious nor dying.

The following language can be added to any Advance Directive or Living Will. There it will serve to advise physicians and family of the wishes of a patient with Alzheimer's Disease or other forms of dementia. You may simply sign and date this form and include it with the form *My Particular Wishes* in your Advance Directive.

If I am unconscious and it is unlikely that I will ever become conscious again, I would like my wishes regarding specific life-sustaining treatments, as indicated on the attached document entitled *My Particular Wishes* to be followed.

If I remain conscious but have a progressive illness that will be fatal and the illness is in an advanced stage, and I am consistently and permanently unable to communicate, swallow food and water safely, care for myself and recognize my family and other people, and it is very unlikely that my condition will substantially improve, I would like my wishes regarding specific life-sustaining treatments, as indicated on the attached document entitled *My Particular Wishes* to be followed.

If I am unable to feed myself while in this condition

I do / do not (circle one) want to be fed.

I hereby incorporate this provision into my durable power of attorney for health care, living will and any other previously executed advance directive for health care decisions.

Signature ______________________ Date ______________

My Particular Wishes

My Particular Wishes for Therapies that Could Sustain Life

In addition to the information on other Advance Directive forms I have completed, I wish to make my instructions known with respect to specific therapies that could save or prolong my life.

This form is meant to inform my physician, nurse or other care provider of my consent or refusal of certain specific therapies. It is also meant to guide my family or any other person I name to make health care decisions for me if I cannot make these decisions myself.

I understand it is impossible to know what a person would want in a particular circumstance, unless that person has previously stated his or her wishes. I hope this document helps those who must make difficult decisions to proceed with comfort and confidence. By following these instructions they know they are acting in my best interests and are consenting or refusing certain therapies just as I would if I could hear, understand and speak.

Decisions While I am Capable

So long as I am able to understand my condition, the nature of any proposed therapy and the consequences of accepting or refusing the therapy, I want to make these decisions myself. I will consult my doctor, family and those close to me, spiritual advisors and others as I choose. But the final decision is mine. If I am unable to make decisions only because I am being kept sedated, I would like the sedation lifted so I can rationally consider my situation and decide to accept or refuse a particular therapy.

Comfort Care

I want any and all therapies to maintain my comfort and dignity. If following my instructions in this document causes uncomfortable symptoms such as pain or breathlessness, I want those symptoms relieved. I desire vigorous treatment of my discomfort, even if the treatment unintentionally causes or hastens my death.

(Continued)

My Particular Wishes

Decisions for Specific Therapies

If my mental or physical state has deteriorated, the prognosis is grave and there is little chance that I will ever regain mental or physical function, I would like the following:

	Yes	Trial period*	No
1. Antibiotics, if I develop a life-threatening infection of any kind.			
2. Dialysis, if my kidneys cease to function, either temporarily or permanently.			
3. Artificial ventilation, if I stop breathing.			
4. Electroshock, if my heart stops beating.			
5. Heart regulating drugs including electrolyte replacement, if my heartbeat becomes irregular.			
6. Cortisone or other steroid therapy, if tissue swelling threatens vital centers in my brain.			
7. Stimulants, diuretics or any other treatment for heart failure, if the strength and function of my heart is impaired.			
8. Blood, plasma or replacement fluids, if I bleed or lose fluid circulating in my body.			

*** This means doctors may see if the therapy quickly reverses my condition. If it does not, I want it discontinued.**

____
Signature

____
Date