

**THE CONSEQUENCES OF LEGALIZED ASSISTED  
SUICIDE AND EUTHANASIA**

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**HEARING**

BEFORE THE

SUBCOMMITTEE ON THE CONSTITUTION,  
CIVIL RIGHTS AND PROPERTY RIGHTS

OF THE

**COMMITTEE ON THE JUDICIARY**

**UNITED STATES SENATE**

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# THE CONSEQUENCES OF LEGALIZED ASSISTED SUICIDE AND EUTHANASIA

THURSDAY, MAY 25, 2006

UNITED STATES SENATE,  
SUBCOMMITTEE ON THE CONSTITUTION, CIVIL RIGHTS AND  
PROPERTY RIGHTS OF THE COMMITTEE ON THE JUDICIARY,  
Washington, DC.

The Subcommittee met, pursuant to notice, at 1:02 p.m., in room SD-226, Dirksen Senate Office Building, Hon. Sam Brownback, Chairman of the Subcommittee, presiding.

Present: Senator Brownback.

## OPENING STATEMENT OF HON. SAM BROWNBACK, A U.S. SENATOR FROM THE STATE OF KANSAS

Chairman BROWNBACK. The hearing will come to order. Thank you all for joining us today. My colleague, and the ranking member, Senator Feingold, I believe will be here shortly. He is carrying an amendment on the floor, and when he comes at the proper time we will have him do an opening statement. But I do want to get this moving forward because we will have votes coming up shortly on the floor and I would like to get as much of the testimony as we can.

The fundamental duty of American Government, and indeed of any government, is to protect and defend the lives of their citizens, the sanctity of the lives of their citizens. It thus becomes the duty of every lawmaker to examine closely any policy that undermines either directly or indirectly the importance and value of each individual's life.

As Chairman of this Subcommittee, I have held hearings examining important issues such as abortion and the death penalty, both of which are legal in the United States, to examine whether they promote or inhibit the culture of life. Today, we will take the next step in this inquiry and focus on assisted suicide and euthanasia, and its effects on society and how we view our fellow human beings.

To be sure, the constitutional question has long been resolved. In a 1997 case called *Washington v. Glucksberg*, the U.S. Supreme Court ruled that the 14th Amendment to the Constitution does not protect a fundamental right to assisted suicide. Recognizing that the state has an interest in protecting human life, the *Glucksberg* court upheld Washington State's ban on assisted suicide. "To hold otherwise," wrote the majority, "would require the invalidation of a consistent and almost universal tradition that has long rejected the asserted right, and continues explicitly to reject it today even

for terminally ill, mentally competent adults.” In order to invent this right, the Court, quote, “would have to reverse centuries of legal doctrine and practice, and strike down the considered policy choice of almost every State,” end quote.

While the decision in *Glucksberg* left the door open for States to permit and regulate assisted suicide, it kept it firmly shut on those who demanded the novel discovery of this so-called individual right. On a State level, legalized assisted suicide is still in its infancy in the United States. Only one State, Oregon, has allowed the practice. Thirty-eight States have formally criminalized assisted suicide, and seven more States prohibit the practice under common law.

This reflects a clear, enduring consensus of the people that assisted suicide is wrong and is objectionable. Nonetheless, a small but vocal minority have continued to push States to permit the practice, claiming that assisted suicide is nothing more than a modern expression of individual liberty. The Oregon law, which was narrowly approved by voters in 1994, permits physician-assisted suicide in cases involving competent terminally ill patients.

According to official reports from doctors assisting patients who have committed suicide, the Oregon law has hastened the death of 246 people. Some suggest this number may be understated because some doctors underreport how often they have prescribed a lethal dose of medication for the purposes of assisting suicide. Senator Wyden, from Oregon, will be here to testify regarding this on the first panel.

Five years ago, the Federal Government determined that the Oregon law was inconsistent with the Controlled Substances Act, the CSA. The CSA authorizes physicians to prescribe federally controlled substances to patients when used for legitimate medical purpose. It also authorizes the Attorney General to revoke a physician's prescription privileges if the physician's actions render his registration inconsistent with the public interest.

In 2001, then-Attorney General John Ashcroft issued a directive that physician-assisted suicide, as permitted by the Oregon law, did not qualify as a legitimate medical purpose under the CSA. As a result, physicians who prescribed lethal doses of controlled substances to patients to induce suicide could be prosecuted and their license to prescribe medicines could be revoked. The State of Oregon sued in Federal court to block this interpretation.

In January of this year, the U.S. Supreme Court held in *Gonzales v. Oregon*—wrongly, in my opinion, but they determined that the CSA did not permit the Attorney General to prohibit doctors in Oregon from prescribing regulated drugs for use in physician-assisted suicide. In his dissent, Justice Scalia observed that the Attorney General's directive was an appropriate interpretation of the CSA. He found it illogical to consider a prescription of a controlled substance to kill another person to be a, quote, “legitimate medical purpose.”

The legalization of assisted suicide and euthanasia would be problematic for numerous reasons. First and foremost, I believe the danger involving involuntary euthanasia is shown by the ominous experience practiced in the Netherlands, and we will have a witness here today to talk about the Netherlands' experience. They

have legalized assisted suicide and there have been numerous cases reported of doctors literally killing their patients without consent.

In 2001, a Dutch doctor was found guilty of murder for euthanizing a patient, but was given no penalty for his action. The court said that he made an error in judgment, but acted in what he believed to be the best interests of his patient. I think most Americans could be quite disturbed that a doctor could act with such blatant disregard and lack of respect for human life, yet not be penalized. Patients who oppose euthanasia would have much to fear if they could no longer trust their own doctor. This nightmare scenario is antithetical to the proper role of a doctor as healer and caregiver.

A second related danger drawn from the Dutch experience is the slippery slope leading to general disrespect for life, particularly when it involves the defenseless. Doctors in the Netherlands moved to allow euthanizing infants with terminal illnesses, highlighting how assisted suicide and euthanasia targets the weakest among us.

Such policies devalue the lives of those who are ill and those with disabilities, but even more insidious is the devaluation of our own lives when we deem a certain population as having little worth. If we fail to recognize the significant contributions to society made by persons with disabilities, the notions that we are all blessed to be alive, that we are a compassionate society and that, above all, we are all equal are all meaningless. I doubt, again, whether Americans want Government to decide which life is worth preserving and which can be destroyed.

Finally, expanding the use of assisted suicide would disregard our considered judgment about self-destructive behavior, which is that it is frequently a cry for help. It is for this reason we usually seek to help those who attempt suicide. Often, it is not death that someone in this situation seeks, but the reassurance that his or her life means something and has value. Particularly when one considers the prominent role played by depression and other psychological conditions, it cannot necessarily be said that a person seeking physician-assisted suicide is making a truly independent decision.

There are many important issues related to this topic that I hope we can explore with our panels today. It is my hope that we can carve out the proper role for lawmakers in fulfilling the Government's duty to promoting life and protecting individual liberties. We have excellent panels of witnesses on this very important topic. First, of course, we will hear from the Senator from Oregon, Senator Wyden, the senior Senator from his State, who has a considered opinion on this and who has been around the topic a great deal of time. We don't necessarily agree on it, but I certainly respect him and his viewpoints and his articulation of those. I look forward to hearing from him.

We will then hear from a panel that will include Julie McMurchie, from Portland, Oregon. Next, we will hear testimony from Hank Reitsema. His grandfather was a victim of legalized euthanasia in the Netherlands. Last on that panel will be Jonathan Imbody, a senior policy analyst at the Christian Medical Associa-

tion. Mr. Imbody has done significant research on personal experience with euthanasia in the Netherlands.

On our next panel, we will hear from Wesley Smith, a Senior Fellow at the Discovery Institute, who has worked on this topic of euthanasia and has written books on it. Kathryn Tucker is Director of Legal Affairs at Compassionate Choices in Seattle, Washington. And then we will hear from Rita Marker, Executive Director of the International Task Force on Euthanasia and Assisted Suicide; Ann Jackson, Executive Director of the Oregon Hospice Association. And, last, we will hear from Diane Coleman, founder of Not Dead Yet, an organization giving a voice to persons with disabilities in this debate.

It is a difficult topic, it is a hard topic. It is a topic involving life and death, choices, and the role of Government, all of which are integrally intertwined.

We will have Senator Feingold's statement when he gets here, but first let's go to Senator Wyden. I look forward to your testimony and your statement.

**STATEMENT OF HON. RON WYDEN, A U.S. SENATOR FROM THE STATE OF OREGON**

Senator WYDEN. Thank you very much, Mr. Chairman, and let me first commend you, Mr. Chairman, and thank you for your thoughtfulness in having me here today. When I asked to testify because, of course, thousands of Oregonians care so much about this issue, it probably would have been pretty easy for you to say, look, time is short and can we do it on another occasion. But you have always gone out of your way to make sure that a debate is fair and that those with whom you might disagree, like myself, on this would have an opportunity to be heard. I just want you to know how much I appreciate that, and thank you for your courtesy today.

Chairman BROWNBACK. Thank you.

Senator WYDEN. Mr. Chairman, when Oregonians first adopted the Death with Dignity Act and then defended it on a second ballot initiative, it seems to me they were sending Government a clear message. When the American people resisted Government interference in the tragic case of the late Terri Schiavo, they too sent their Government a strong message. That message is that death and end-of-life care is an intensely personal and private moment, and at those moments the Government ought to leave its people alone. The Government ought not to attempt to override or preempt the individual and the family values, religious beliefs or wishes.

I have said before, and just would repeat it here today, I personally voted against physician aid in dying both as an Oregon voter and as a Senator. As the former director of the Oregon Gray Panthers, a seniors advocacy group, I saw firsthand how many poor and vulnerable individuals received inadequate health care. I worried primarily about the adequacy of the ballot measure safeguards to protect poor older people, and as a result I voted against the Oregon ballot measure not once, but twice, as a private citizen.

Despite my personal objections, I firmly believe that my election certificate doesn't give me the authority or the right to substitute



my personal and religious beliefs for judgments made twice by the people of our State. I will continue to strongly oppose any legislative or administrative effort to overturn or nullify the will of Oregon voters on this matter.

Now, had Oregon acted with haste or without a thorough examination and debate, I wouldn't be in much of a position to defend the Oregon law. But certainly nobody can accuse the people of my State of acting precipitously in approving this measure. The voters of Oregon did so after two lengthy and exhaustive debates, Mr. Chairman, that dominates the water coolers and dinner table conversation of the people of my State like nothing else.

The issue of physician aid in dying is settled as far as my State of Oregon is concerned. My State has endured two legal ballot initiatives, court challenges to stop the implementation of the law, attempts in Congress to overturn the law, an attempt to overturn the law through administrative action by the Federal Government, and finally a challenge that went to the U.S. Supreme Court. At each stage of this lengthy discussion, the will of a majority of Oregonians prevailed.

During the eight years the law has been in effect, the opponents of the law have combed through it to look for possible pitfalls. However, the law still stands. During the 8 years the law has been in effect, the opponents said that there would be abuses and that there would be a stampede to Oregon. The law has not been abused. In fact, over 8 years, an average of about 30 Oregonians a year have used lethal prescriptions. This, of course, is a small fraction of Oregonians who faced terminal illness during that period.

While I do not know how I would vote were the issue to appear on the Oregon ballot once more, I believe that it is time at least for me to acknowledge that my fears concerning the poor elderly were thankfully never realized, and the safeguards appear to have worked well in preventing potential abuses.

What is often not discussed by opponents of the Oregon law is the Oregon Death with Dignity Act has brought about many improvements that are widely supported by all parties to this discussion in end-of-life care. For example, pain management has improved. My State remains the only State to discipline a physician for the under-treatment of pain. However, perhaps the most important side effect of the law is that families, health professionals and patients know they can and should have conversations about how they want to handle these extraordinarily difficult end-of-life challenges and what their wishes are with respect to treatment.

In 1997, the U.S. Supreme Court decided two important cases that should inform this discussion. The Court, in *Washington v. Glucksberg* and in the *Vacco* case, rejected any constitutional right of terminally ill patients to physician aid in dying. But more importantly, the Court in those decisions left the States free to permit or prohibit assistance in end-of-life matters such as dying.

Indeed, the High Court encouraged States to proceed with their various initiatives in this area. So Oregon did, in fact, exactly what the Court encouraged be done. Historically and constitutionally, States have always possessed the clear authority to determine acceptable medical practice within their borders. States are respon-

sible for regulating medical, pharmacy and nursing practice. Even the preamble to Medicare states, "Nothing in this title shall be construed to authorize any Federal officer or employee to exercise any jurisdiction or control over the practice of medicine or the manner in which medical services are provided."

The scientific health literature is full of studies documenting how medical practice differs from region to region, State to State, and sometimes from medical institution to medical institution. End-of-life care, in my view, should be no different.

While other States have considered physician aid in dying since Oregon passed and implemented the Death with Dignity Act, they have not adopted it. I respect their choice, Mr. Chairman. Yet, no one challenged their decisions in court. Neither the Congress nor the administration attempted to overturn those decisions. Oregon's decision, reached through legal means, ought to be respected as well. Fair-weather friends of States' rights should be reminded that States' rights does not mean just when you think a State is right.

Mr. Chairman, I want to end by saying that it is my hope—and that is why I always appreciate the opportunity to talk with you about these and other issues—that we could find some common ground here, that we could find some ground where all sides could come together and thereby focus our efforts on those kinds of areas.

I know of no member of the U.S. Senate, Mr. Chairman, who doesn't want to reduce the desire and demand for physician assistance in terms of working through those difficult decisions. In order to do that, pain management needs a huge boost, not another setback. Previous attempts to negate Oregon's law have damaged pain management in every part of our country. Even the *New England Journal of Medicine* editorialized against that attempt out of concern for the impact on pain management nationwide. They said many doctors are concerned about the scrutiny they invite when they prescribe or administer controlled substances, and they are hypersensitive to drug-seeking behavior in patients. Patients, as well as doctors, often have exaggerated fears of addiction and the side effects of narcotics. Congress would make this bad situation worse.

It is my view that pain management has a long way to go in this country, Mr. Chairman. Senator Smith and I introduced something that we thought could be the bipartisan basis of bringing people together around this issue, and it is called the Conquering Pain Act. What Senator Smith and I seek to do is to help provide families, patients and health professionals with 24/7 assistance so that no patient anywhere in this country would be left in excruciating pain waiting for a doctor's office to open up.

Another area that I think would be ripe for bipartisan efforts to find common ground is in the Medicare hospice benefit, Mr. Chairman. I have legislation, the Medicare Hospice Demonstration Act, to test new ways of bringing hospice benefits to the patient. For example, Medicare currently requires terminally ill patients to choose between so-called curative care and hospice. In plain English, that means that you can't get hospice benefits unless you give up hope in our country. That makes no sense, and I contend that people do not get into hospice soon enough to get its full benefits if they are forced to make this kind of choice. The idea that I have—and the

Aetna Company is now testing it—would set aside this either/or choice and allow hospice to begin while the patient continues with curative care.

Finally, the Nation also has a shortage of providers, physicians and nurses who are trained in palliative care essentially, or what is also known as comfort care. The legislation that I authored here provides funding to assure that there is a medical faculty trained in comfort care for all ages. It is a sad fact that not everyone can be cured. As the number of ways to prolong life multiplies, end-of-life care issues are going to be more controversial, more difficult and more painful. The aging of our population will bring more families face to face with these issues.

I contend that the more that is done to improve end-of-life care and to help support patient and family decisions, the less people will turn to physician aid in dying. For the citizens of Oregon, the Death with Dignity Act has brought about improvement in many areas and encouraged conversations that many would not have had. For many, it has brought a small measure of peace of mind knowing that they can remain in control of their lives if they choose to do so. It has decriminalized the end-of-life process.

You can never prove a negative, Mr. Chairman, and I am not here to offer some kind of scientifically based theory. But I actually believe in Oregon, because of all of the debate we have had and because we have seen an increase in the use of hospice, an increase in the number of folks who spend their last days at home—I believe in Oregon we have fewer physician aid in dying cases than in other States where that kind of action is prohibited.

Mr. Chairman, I know these are deeply personal issues. My State has chosen a unique path, but rather than pursue a bitter and divisive debate over physician aid in dying, what I want to do today, in addition to defending the law that has been adopted for my State, is to also outline a number of approaches such as that Senator Smith and I have proposed that could bring together the Senate and people of differing views on this issue in a fashion that would be good for our country.

Chairman BROWNBACK. Thank you very much, Senator Wyden, and thank you for your very thoughtful, very dignified, and continued effort to try to bring people together on tough subjects. That is quite laudable and necessary to ever move much of anything forward and I appreciate it greatly.

Senator WYDEN. Thank you, Mr. Chairman.

Chairman BROWNBACK. The next panel will consist of three panel on the panel, if they could come forward now: Julie McMurchie, of Portland, Oregon; Hendrick Reitsema from the Netherlands; and Jonathan Imbody from Ashburn, Virginia.

I am told that Senator Feingold remains on the floor with an amendment, so we are going to continue to proceed forward. We will put all of your formal statements into the record, if you would care to summarize. I would like to run the clock at 6 minutes to give you an idea where you are just so we can get as much testimony in as possible.

Ms. McMurchie.

**STATEMENT OF JULIE S. MCMURCHIE, PORTLAND, OREGON**

Ms. MCMURCHIE. Mr. Chairman, thank you for inviting me. I am here to tell the story of my mother, who used Oregon's law 5 years ago to end her life after a long battle with lung cancer.

I would like to start out by asking that you refrain from using the term "suicide" in this context. I think it demeans my mother's memory. To paraphrase the mental health amici in *Oregon v. Gonzales*, "End-of-life decisions by terminally ill patients are in no way related to what is commonly termed suicide, which is considered to be a self-destructive act often related to clinical depression." My mother was not depressed when she made the decision to hasten her death.

A decision to hasten death is more accurately parallel to a patient's thoughtful decision to decline life-sustaining treatments, a product of judgment and reason based on the desire to maintain one's dignity in a period where death is pending. That reason and judgment is fundamentally different from the reasoning a clinically depressed person uses to justify suicide.

On January 25, 2001, my mother, Peggy Sutherland, a 67-year-old lifelong registered Republican, hastened her death under the rights afforded to her by Oregon's death with dignity law. I would like to start out today by telling you a little about her background.

My mother grew up in a very traditional household on the Philadelphia Main Line. She was raised to do what she was told and was given little freedom to make decisions for herself. She did what her parents and society expected of her, and when she graduate from a women's Ivy League college, she immediately married my father and supported him while he went through medical school.

When it came time for my father to decide where to start his practice, they decided to move to Oregon. My mother had never been west of the Mississippi and she moved her entire family across the country based on one photograph of the Oregon coast.

My mom loved Oregon. She often talked about the constraints and societal expectations that had burdened her in the East and how much she loved the free thinkers and independent thought that she found in Oregon. She was intellectual and practical, and raised my four siblings and I to evaluate and make our own decisions and to take care of ourselves.

In January of 2000, my mother was diagnosed with lung cancer. She had a surgery to remove the tumor and was pronounced cured, though, of course, she was not. When the tumor returned a few months later, she had another surgery to remove her lung. Each of these surgeries was an enormous undertaking and she had a great deal of pain and long recoveries.

In June of that year, my mother's sister in Pennsylvania was also diagnosed with lung cancer. My aunt spent 100 days in a small hospital room prior to her natural death. Most of that time, she was in a coma and her three sons did their best to travel from Seattle, Florida and Geneva to spend time in that small hospital room.

My mother and I visited my aunt several times and it became very clear to my mom that she did not want that death for herself or her family. In August of 2000, she was diagnosed as terminal and began talking to her children about hastening her death under

Oregon's law. Over the next 4 months, she had multiple hospitalizations, CT scans, PET scans, bone scans, chemotherapy, and radiation treatments. I went with her to almost every one of her doctor appointments and treatment appointments.

At the same time, though, she very much continued to make the most of every single day. She stayed very active in her book club, her bridge club, and in the lives of her five children and nine grandchildren. I wanted my mom to come and live with me during her last months, but she really didn't want to do that. She wanted to be independent. She had a great apartment overlooking the Willamette River and she loved it there, and that is where she was most comfortable and that is where she wanted to be. So I respected that.

One morning in December, my mom woke up and could not get out of bed because the pain was too great. She was hospitalized for 3 weeks while we tried to control the pain well enough to fulfill her wishes and take her to the Oregon coast to die. She had two M.D. pain specialists attending her during those 3 weeks, and had a morphine pump installed directly into her spine.

This next point I think is very important. I have two siblings who are physicians, very sophisticated physicians, and they are both married to physicians. My mom and dad, while my parents were divorced when she died, had been married for 40 years and my dad is a cardiologist. My mother had the most sophisticated medical and palliative care available. She had more doctors than anyone knew what to do with and we were all paying very close attention to her care.

I remember very clearly when my mom made the decision to switch from trying everything to stay alive one more day to letting go and allowing herself to die. She came home from that last 3-week hospital stay and made her first request to hasten her death under Oregon's law. This request was very consistent with my mom's personality and with the forthrightness and acceptance with which she had treated her illness and terminal diagnosis.

My three sisters, my brother and I all immediately supported her. After watching this disease ravage her body and after watching the dignity and grace with which she had handled a terrible year, we all felt she deserved this final bit of control. She failed rapidly during the 15 days of the mandatory waiting period under the law. She had been bedridden for 6 weeks and had lost control of her bodily functions. She began having difficulty breathing because of the tumors growing in her airways and she began coughing up blood. My sister, who is a pulmonologist, began to worry that she would hemorrhage in her lungs and drown.

On the morning of January 25, 2001, my mom made her final request to end her suffering and use Oregon's death with dignity law. On that morning, she lay in her own bed, in her own room, surrounded by her five children, our five spouses, her remaining sister and a nephew, and her long-time internist and friend.

We read some poetry. We listened to some music, and she wanted to hear the 23rd Psalm. We all hugged her, kissed her and told her how much we loved her. Her final words before she drank the medication were "I don't think anyone has realized how much pain

I have been in.” She drank the medication and fell peacefully into a coma within 5 minutes. Fifteen minutes after that, she died.

I feel that my family was given a gift that morning. My final memories of my mother are profoundly loving and supportive. May we all be so lucky to die surrounded by those we love the most in the world. May we all be so lucky to have the last eyes we see and the last touch we feel be that of our children.

The inevitability of my mother’s death from her disease was not in question. Her choice to hasten that inevitability was a reflection of her values and emblematic of the personal freedom our country prizes. Her choice was not about making that choice for others, as in euthanasia, nor was it in any way about demeaning the life of or compromising the rights of people with disabilities. Her choice in no way degraded or sought to critique the end-of-life choices that others with different values make everyday.

On the contrary, my mother would have wanted people with different values, whether grounded in their religion or otherwise, to be able to make their own choices about how their lives come to an end when faced with a terminal diagnosis. Oregon’s law is about preserving those choices for everyone.

Thank you very much.

[The prepared statement of Ms. McMurchie appears as a submission for the record.]

Chairman BROWBACK. Thank you for a very touching statement, and I appreciate your willingness to travel here and your willingness to give it. That had to be very difficult to do. Thank you for doing it.

Mr. Reitsema, thank you very much, as well, for traveling here to speak to the Subcommittee.

**STATEMENT OF HENDRICK REITSEMA, ECK EN WIEL, THE  
NETHERLANDS**

Mr. REITSEMA. Thank you very much for the privilege of testifying today, Mr. Chairman. I too agree that dying with dignity is dying being loved by others. Dignity is something that is attributed and given, not something that we possess by ourselves.

It was January 1996 that my Dutch grandfather was euthanized in an old people’s home in the north of the Netherlands. My family has never quite been the same since then, and I would like to impress upon you and all present that policymaking relating to life and death has massive consequences for all those people involved and the families around people who are touched by these policies.

Since that event in 1996, I have done my level best to keep up with the developments in the Netherlands and the policies relating to euthanasia and physician-assisted suicide. I would like to share a snapshot of that development and how it has impacted my own family.

I was visiting my grandfather at the beginning of the week that he was killed, unaware, as the rest of my family, that a treatment of morphine overdose and starvation was being applied to him. My “opa,” as I called him, being a rather stubborn individual and a very devout Christian man, had had a stroke a couple of years prior to that, and he for that reason was partially paralyzed on one side and needed the care that you get in a nursing home.

My grandmother, who lived two street blocks away from this nursing home, visited him everyday, and many cousins often visited my grandfather, as did I, because he was an awful lot of fun to be around, a real patriarch of this close-knit and large family. It is very unlikely that this man who loved life so much and was mentally still so much up and with it—he could play a very good game of cards right up to close before he died—it is very unlikely that he would have expressed the desire to die. It would have flown against everything that he believed.

Yet, the medical staff that surrounded him was working on what they perceived as providing a speedy and dignified and painless death, as they saw it. Now, take note that the Dutch are not some kind of monsters. The fact that we as a society have embraced euthanasia and assisted suicide is not because we disrespect life in the first place, but because of the motivation to fight suffering. The consequences, though, have been disastrous for many of us.

By the mid-1990's, this kind of procedure, when requested by ailing patients, was not at all uncommon in Dutch medical facilities. It all started basically in 1973 with the Geetruida Postma case, and through a series of court decisions and medical association guidelines, the parameters for assisted suicide and euthanasia which proved to be inextricably linked because of the involvement of the physician and the motivation to fight suffering—these decisions broadened the parameters to the situation in 2002 when it was formally legalized.

In that trajectory, a set of criteria were formulated. Basically, they boil down to patient consent, to suffering that is unbearable without the prospect of improvement, being well-informed and consulting at least one independent physician.

In my grandfather's case, it is rather clear that what happened did not meet these criteria very well, the primary reason being that what happened in his treatment was not really being considered euthanasia, euthanasia being reserved only for active killing with lethal injection under sedation, with the immediate result of dying. Let's say the extension of using pain treatment to end life was more what happened in his case.

Let's say the shifting tide in terms of the terminology has also produced a sort of vague, unclear zone, a gray area where a lot more people are confronted with physicians making active decisions about death than those that are reported in the formal Government reports.

He was diagnosed with lymph cancer in December 1996, and in January 1996 the doctor decided, when he asked for pain relief treatment for a thrombotic leg, to instigate progressive morphine application and subsequent withholding of food. I visited him and was surprised at how fast he was deteriorating. At the end of that week, my aunt was visiting and she was feeding him some water at the moment when one of the nursing staff said, don't do that, you are prolonging his death. This was the moment when the family discovered what was happening.

Needless to say, pandemonium broke loose and we tried to reverse the situation unsuccessfully. He had already contracted pneumonia from the morphine overdose, which makes your tongue swell and makes it hard to get the phlegm out. He died the next day,

and the death reason on his death certificate was listed as pneumonia, not active activity of physicians.

The impact on our family was massive. My father, who had been living in South Africa for 35 years, at that point already sometimes feeling guilty for being so far away, had planned a trip in March the moment he heard that my grandfather was ill. He never got the opportunity to do that. He had to shift the ticket to go to a funeral. My grandfather would probably have had about 3 years to live, given the prognosis. My sister is a physician and she surmised that it would have been roughly three years.

In all of this, my grandmother was feeling pressured into agreeing with some kind of pain treatment she didn't understand. I find that the most cruel event in what happened to the family. She agreed because of respect for the medical profession to whatever the doctors thought was good, not understanding the exact implications, and later was so traumatized by it that she for the rest of her life had a hard time talking about the whole event around my grandfather's death. She herself in the end moved 200 kilometers, which in the Netherlands is a long way—that is halfway through our country—to be in a nursing home herself when she became infirm, where she would be guaranteed that they would respect her life. That meant that she had been to be away from all the people that she had relationships with close to home and it meant that she was afraid of the medical system.

I think the Dutch legal system has gotten itself into a catch—22, that of trying to legalize for the sake of fighting pain and suffering, but in so doing having to provide some kind of immunity for doctors before they are willing to report their activity. The result is that only 40 to 50 percent is being reported at present, and that can hardly be considered an effective policy.

I thank you for listening.

[The prepared statement of Mr. Reitsema appears as a submission for the record.]

Chairman BROWNBACK. Thank you for talking about another tough family situation and the practical events that happen.

Mr. Imbody, thank you for joining us.

**STATEMENT OF JONATHAN IMBODY, SENIOR POLICY ANALYST, CHRISTIAN MEDICAL ASSOCIATION, ASHBURN, VIRGINIA**

Mr. IMBODY. Senator Brownback, thank you for this privilege of testifying. I serve as senior policy analyst with the Christian Medical Association, a professional organization of 17,000 members.

I spent several months in the Netherlands a few years ago researching personal accounts of euthanasia. I knew from published medical studies that Dutch doctors admitted, on condition of anonymity, to putting approximately 1,000 patients to death a year without the patient's request.

I interviewed Dr. Zbigniew Zylicz, a Polish-born internal medicine and oncology specialist who practiced in the Netherlands since 1979. Dr. Zylicz told me about his experience with an elderly patient in an academic hospital. He said, "My patient was afraid to go to the hospital," similar to Mr. Reitsema's grandmother, "because she was afraid of euthanasia. She was not asking for this.



She did not even want this, and they promised her that nothing would happen to her. I admitted her on the weekend to a bed of another patient who would be coming back Monday morning. I had no other facility for her. She was very ill and I expected she would die on the weekend, but she improved. With good treatment and pain control, she started to talk and she was not dead. On Monday morning when I went off my shift and went home, my colleague came and did something. I don't know exactly what he did, but she died within 10 minutes. And the nurses called me at home. They were very upset about this and I was very upset about this, too. Dr. Zylitz added, and this was not the only single case. This was the whole system working like this."

The Dutch have a lot of faith in their dikes and in their regulations, but euthanasia introduces dangerous gray areas of decision-making by doctors and by vulnerable patients who feel pressured to die. These gray areas defy regulation.

I interviewed a Dutch couple, Ed and Xandra, who told me about Ed's father, Franz. Franz was a Dutch sailor who had reluctantly entered the hospital for pain relief. The doctors discovered that Franz had a terminal illness.

Franz's son, Ed, recalls, "We were all invited to the hospital when [the doctors] said the diagnosis. The doctors told my dad, well, you don't have too long to live. We can't guarantee anything, but if we operate, you could live longer and have more time to be with your kids." Ed recalls, "When the doctors left, my sister said it very bluntly, just putting it on the table. 'What about euthanasia', she said."

Franz's wife didn't protest. Xandra suggests that is because Franz's wife was angry with him and thought Franz had been unfaithful in their marriage. So Franz agreed to euthanasia.

Xandra remembers the day the doctor came to put her father-in-law to death. She said, "[The doctor] had all those little vials, and she had two injections, one to put him to sleep and one for the killing part. She was, OK, I need to do this now. Probably, she had another appointment after that."

"Then she started injecting him," Xandra recalls. "While she was giving the injection, I was standing at my father-in-law's feet. He was really looking at me and at our baby. I was holding the baby at the time." Then Xandra says her father-in-law suddenly cried out. He said, "I don't want to die."

Xandra frantically looked to the doctor and at the others in the room, "but no one was reacting," she recalls. She didn't know what to do. "And then," she says, "he was like he was in a deep sleep. So then the doctor started getting the other injection. Then I left the room." Franz died from that second injection, whether he really wanted to or not.

Once a country casts off millennia of Hippocratic and Judeo-Christian prohibitions against suicide and euthanasia, the ship drifts farther and farther out to sea with no anchor. If we assume the power to kill patients who ask for it, why not kill disabled patients who cannot ask for it? If we assume the power to kill patients with physical illnesses, why not kill patients with emotional illnesses? If we assume the power to kill the elderly who have medical problems, why not kill infants who have medical problems?

This slippery slope is not theoretical. This is exactly what has happened in the Netherlands, and it can happen anywhere unless we provide truly compassionate alternatives to state-sponsored suicide. More doctors need advanced training in palliative care. In certain cases, more aggressive pain relief prescribing regulations will help doctors provide more effective relief for patients. Hospice care can provide tremendous benefits for patients and families.

And this is something on which I think we all agree: Perhaps the most important help for terminally ill patients transcends medicine. The unconditional, persevering love of family, friends and God can provide us with incomparable strength, courage and hope beyond our physical condition.

Thank you.

[The prepared statement of Mr. Imbody appears as a submission for the record.]

Chairman BROWNBACk. Thank you very much, Mr. Imbody. Mr. Imbody, did you do a full report on the series of interviews that you did in the Netherlands?

Mr. IMBODY. I have not. I have written a few articles, but I have not put it together in a full report.

Chairman BROWNBACk. If you wouldn't mind submitting for the record the articles, I would appreciate it, because if you did a series of interviews, it would be, I think, a good accumulation of information for us to be able to have as an examination for the Committee.

Mr. IMBODY. I will.

Chairman BROWNBACk. The Netherlands situation, Mr. Reitsema, you said started in 1973 when the law passed, or was it a court interpretation? What happened in the Netherlands?

Mr. REITSEMA. It was a court interpretation where a physician aided her mother in killing her mother, euthanizing her. And the court, though they found her guilty of the crime of euthanasia, only applied a 1-week suspended sentence to her at that point. And this was the start of the courts giving a signal that as long as the criteria which the colleagues testified to in that court case, the physician colleagues of the physician involved—as long as those criteria of, let's say, careful due process were being held to, the courts would then not litigate against or apply penalties against. So there was this development.

The Dutch know more policy areas where we have what we call hedogbleit; i.e., something is formally illegal, but with a series of court decisions showing there will not be prosecution, it creates space for people as long as they are in contact with the Ministry of Justice and short of checking up—

Chairman BROWNBACk. So you can do it. It is illegal, but there is no penalty?

Mr. REITSEMA. Illegal, but no penalty, and to a certain extent having the blessing of the Ministry of Justice.

Chairman BROWNBACk. This started in 1973 and then has been—

Mr. REITSEMA. 1973, and slowly progressed right until 2002, where those criteria, basically the same criteria which were formulated then, became law, formalized law. Just in this last year, at the end of 2004 going into 2005, we have had the same process happening with infanticide where these basic criteria, save for pa-

tient consent, because babies are not capable of that, have been applied to infants in cases of unbearable suffering, et cetera.

So the Department of Justice has agreed to not prosecute doctors as long as they stick within the parameters of this set of criteria. The Department of Justice has no intention of formally legalizing euthanasia for babies, or infanticide, at this point.

Chairman BROWNBACk. How many cases of euthanasia a year now in the Netherlands? If you know particularly those of infants, I would like to know the number.

Mr. REITSEMA. I will start with the question of adult euthanasia. It depends upon how you define euthanasia. The way the Department of Justice is defining it, there are about 3,500 cases of assisted suicide and euthanasia.

Chairman BROWNBACk. In a population of how many?

Mr. REITSEMA. In a population of 17 million people. If one includes terminal sedation, as it is being called, which means putting somebody into a subconscious sleep state and not feeding them artificially, which is the only way you can feed somebody who is sedated, that number would increase to be about 14,000 people of, let's say, the formally registered, which is about 10 percent of all deaths in the Netherlands. So about 10 percent of all deaths in the Netherlands at the moment have a physician-assisted component in the killing. That would be equivalent to about 420,000 people in the USA if you would compute it on the population here.

Chairman BROWNBACk. And infants?

Mr. REITSEMA. In infants, there is a report between 1997 and 2004 where 22 cases were formally reported over that whole period. Government studies show that there are about 20 cases, where an independent British medical journal study shows that there were almost 100 cases, 20 with lethal injection and 80 by the withholding of food and the necessary means to stay alive. So probably about 100 per year is an accurate figure.

Chairman BROWNBACk. Do we have other countries to track that have had this much experience with euthanasia. The Netherlands is well-known. To me, it is always worthwhile to look at what has been the experience of other countries.

Mr. REITSEMA. The Netherlands is unique in terms of the length of history with these policies, but a country like Belgium has similarly legalized up to a certain extent. The numbers in the Belgian situation are much lower than in the Netherlands.

Chairman BROWNBACk. I want to thank the panel, and particularly, Ms. McMURCHIE, on your closeness to the difficulty. My apologies for language used that offended you. I did not intend to do that and I apologize to you for that.

One of my biggest concerns here is where does this go once you start in it, and that is why the questioning here. And if you want to respond to that, I would be happy to have you respond to that point, because when you start down these policy roads, that is always a point you are really wondering at the end of it. Where does this go to? A lot of times, we are just trying to do what is good right, and then you get 20 years down the road and you ask how did we get here.

Ms. McMURCHIE. Oregon's law has very defined and very clear safeguards to keep us from approaching that slippery slope. As you

said—and Kathryn Tucker can talk more about this; she knows a lot more than I do—in the *Glucksberg* case, it was sent back to our State as a test tube, if you will, to see how those safeguards would work, and it has worked beautifully.

There have been zero reports of abuses, zero reports of coercion in this law. It is very much the individual's choice. The safeguards include waiting periods, specific requests made both in writing and verbally. The medication has to be self-administered. My mother had to be able to hold that medication in a glass by herself and drink it by herself. We couldn't touch it. And that is what she did.

There has just been nothing to suggest that any of these fears—I mean, euthanasia is such a completely different issue than Oregon's aid in dying law, completely different, and I have great respect for that difference. This is very much a personal choice about one's own impending death. This isn't about anyone trying to coerce a disabled person. It is not saying anything about a disabled person's life or the value of that life whatsoever. It has nothing to do with that. It is an individual person's choice.

We keep a lot of data in Oregon and Compassion and Choices has a lot of data about the motivations that the individuals that use the law or request the law—the motivations that cause them to do so, and it is all about autonomy and enjoying life and a little bit about pain control. It is not about money. It is not about anything other than that personal choice.

Chairman BROWNBACK. I appreciate that. The concern is that the Netherlands came into this by a daughter trying to help her mother in a difficult situation, and then you are 30 years out and you have got the kinds of numbers even on infants that you are looking at. When you enter that policy field and you are saying, OK, we are going to say this is all right, where do you end up?

Ms. MCMURCHIE. But they take the choices away from the individual, which we do not at all in any way do.

Chairman BROWNBACK. I thank the panel very much.

Ms. MCMURCHIE. Thank you very much.

Chairman BROWNBACK. I will call up Wesley Smith, a Senior Fellow at the Discovery Institute; Kathryn Tucker, Director of Legal Affairs, Compassion and Choices; Rita Marker; Ann Jackson; and Diane Coleman.

If I could ask this panel if you would stick to the timeframes, we have got a large panel and I am told a vote in 45 minutes and I would like to conclude this by that period of time. So if we could stay with your timeframes, I would certainly appreciate that.

Mr. Smith, thank you for joining us.

**STATEMENT OF WESLEY J. SMITH, SENIOR FELLOW,  
DISCOVERY INSTITUTE, CASTRO VALLEY, CALIFORNIA**

Mr. SMITH. Thank you, Senator Brownback, for having me. I appreciate it very much. I will omit my biographical data, since it is attached to my written testimony, and go right into the presentation.

Chairman BROWNBACK. Please, and all of your written testimony will be included in the record, so you can summarize.

Mr. SMITH. Thank you.

I appear today to argue that there is a proper public policy role for the Federal Government against assisted suicide, such as prohibiting federally controlled substances from being used to intentionally end life and in the application of other Government policies consistent with the standards of federalism. This would be in keeping with the existing Government policy that prohibits Federal money from being used to fund assisted suicide under the Medicaid program.

There are two deep ideological beliefs asserted by advocates for justifying the legalization of assisted suicide. The first is a radical individualism that perceives personal autonomy as being virtually absolute, as including the individual's right to self-determination, including a right to control the time, place and manner of death. The second ideological principle underlying assisted suicide is that killing, which simply means ending life—that is descriptive—can be an acceptable answer to the problem of human suffering.

Assisted suicide advocacy in the U.S. is usually couched in terms that would limit assisted suicide to those who are terminally ill. But given the philosophical and ideological principles that underlie the assisted suicide movement that autonomy is paramount and killing is a valid answer to human suffering, restricting assisted suicide to the dying becomes utterly illogical. After all, many people experience far greater suffering and for a far longer period than people who are terminally ill.

Thus, once the premises of assisted suicide advocacy become accepted by a broad swath of the medical professions and the public, there seems little chance that the eligibility for permitted suicide will remain limited to the terminally ill. We need only look to the experience of the Netherlands to see the destructive force that the implacable logic of assisted suicide ideology unleashes.

The Dutch have permitted euthanasia and assisted suicide since 1973, when it was, in essence, decriminalized by a court ruling so long as certain protective guidelines were followed. And as you heard, they were formally legalized in 2002. In actual practices, these guidelines have provided scant protection for the weak, vulnerable and despairing.

Indeed, since 1973, Dutch doctors have gone from killing terminally ill people who ask for it, to chronically ill people who ask for it, to disabled people who ask for it, to people who aren't sick but depressed who ask for it. The assisted suicide of depressed people was explicitly approved by the Dutch supreme court in the death of Hilly Bosscher. Bosscher wanted to kill herself because she had lost her two sons. Bosscher had one desire left in life, which was to be buried between her two dead children.

Her psychiatrist, Dr. Boudewijn Chabot, met with her on four occasions without attempting to treat her. Believing her to be suffering from what he called incurable grief, he helped Bosscher kill herself. The Dutch supreme court validated Chabot's actions on the basis that the law cannot distinguish between suffering caused by physical illness and suffering caused by mental anguish.

In the Netherlands, infants are killed by doctors because they have birth defects. A 1997 study published in the British medical journal, the *Lancet*, revealed how deeply pediatric euthanasia had

implanted itself into Dutch neo-natal medical practice. And as you heard, that amounts to almost 100 babies per year.

Dutch doctors also euthanize people who have not asked to be killed. This practice even has a name—termination without request or consent. Dutch Government studies show that at least 900 such people are killed each year, and even though this is murder under Dutch law, virtually nothing meaningful is ever done about it.

The Netherlands is a very small country, Mr. Chairman, with about 130,000 total deaths per year. We are not small. About 2 million of us die each year. To see the death toll that would occur in the United States if assisted suicide became normalized, we need only apply Dutch euthanasia statistics to the United States population, and these are older statistics in which fewer people were being euthanized based on the Rummelink report of 1990.

In that year, 2,700 patients were euthanized or assisted in suicide by their doctors upon request. We are not talking about involuntary or nonvoluntary—upon request. Based on our higher population, the equivalent number of deaths by assisted suicide in the United States would be approximately 41,500 hastened deaths per year. Clearly, the stakes for America's seriously ill, disabled and elderly patients in this debate are very high indeed.

I would like to finish my testimony by quoting a friend of mine who died of ALS. His name was Bob Salamanca, and I met him as a hospice volunteer. I had been a hospice volunteer. I was trained specifically as a hospice volunteer that if any patient was suicidal, I was to tell the team so that intervention could be done to prevent the suicide—suicide prevention, which almost always works when it is actually applied. It doesn't always work, but it quite frequently does.

Bob Salamanca was quite aware of the debate about assisted suicide, and he was spitting nails because what he said was, you know, if somebody has one situation for wanting suicide, the state will prevent it, but if I ask for suicide, some people say the state should permit it to be facilitated. And he wrote a piece in the 1997 San Francisco Chronicle and this is what he said, and I would like his voice to be heard.

"Euthanasia advocates believe they are doing people like me a favor. They are not. The negative emotions toward the terminally ill and disabled generated by their advocacy is actually at the expense of the dying and their families and friends, who often feel disheartened and without self-assurance because of a false picture of what it is like to die created by these enthusiasts who prey on the misinformed. What we the terminally ill need is exactly the opposite, to realize how important our lives are, and our loved ones, friends, and indeed society need to help us to feel that we are loved and appreciated unconditionally."

Bob Salamanca died peacefully in his sleep of Lou Gehrig's disease. I gave his eulogy, and he would be so proud today to be able to have testified in front of this panel.

Thank you.

[The prepared statement of Mr. Smith appears as a submission for the record.]

Chairman BROWNBACK. That is very powerful, very good.  
Professor Tucker.

**STATEMENT OF KATHRYN TUCKER, DIRECTOR OF LEGAL AFFAIRS, COMPASSION AND CHOICES, AND AFFILIATE PROFESSOR OF LAW, UNIVERSITY OF WASHINGTON SCHOOL OF LAW, SEATTLE, WASHINGTON**

Ms. TUCKER. Thank you. Good afternoon. Thanks for inviting me to testify at this important hearing. As Legal Director for Compassion and Choices, I speak on behalf of our supporters who strongly believe, as do a majority of Americans, that dying patients should be empowered to control their dying process.

Even with excellent pain and symptom management, a fraction of dying patients will confront a dying process so prolonged and marked by such extreme suffering and deterioration that they determine that hastening their own impending death is their least worst alternative.

I represented the patients in the *Glucksberg* and *Quill* cases and in the *Oregon v. Gonzales* case, so I do know a bit about this area. In *Glucksberg* and *Quill*, the terminally ill patients and physicians brought action against the States of Washington and New York for States laws that criminalized so-called assisted suicide to the extent that it would apply to a mentally competent, terminally ill patient who wanted to control the time and manner of death.

They sought the right to do so under the Federal Constitution. Those claims were successful in both the Second and Ninth Circuit Courts of Appeals. The U.S. Supreme Court refrained from finding a Federal constitutional right in 1997, believing that the issue should be left to the States in the first instance. And the Court's decision encouraged the earnest and profound debate about the matter to continue.

Eight years of experience in Oregon—Ann Jackson will testify to that. I won't speak in great detail in deference to her testimony. However, I will say that with this 8 years of experience, objective observers nationwide have now published studies and publicly spoken out that what we can see from Oregon is that—and here is a quote from the State of Vermont examining this question, quote, "It is quite apparent from credible sources in and out of Oregon that the Death with Dignity Act has not had an adverse impact on end-of-life care, and in all probability has enhanced other options."

The Director of Bioethics at Pennsylvania Medical School, an objective outside observer, said after reviewing the Oregon data, quote, "I was worried about people being pressured to do this, but the data confirms that the policy in Oregon is working. There is no evidence of abuse, coercion or misuse."

Just recently this term, the American Public Health Association submitted an amicus brief to the U.S. Supreme Court in the *Gonzales v. Oregon* case in which the group advised the Court that researchers have consistently found that the experience in Oregon does not bear out concerns that physician-assistance would be disproportionately chosen by or forced on terminally ill patients who are poor, uneducated, uninsured, or fearful of financial consequences of their illness.

Terminally ill Oregonians do not choose assisted dying because they have untreated pain. On the contrary, Oregonians have access to good pain and symptom management. Only the relatively few who find that the cumulative burden of their illness is intolerable

persist in the desire to hasten death and go on to use the Dignity Act.

Nationwide, although Oregon is yet the only State to legalize this option, support is wide and deep. All of the polling shows 65 or 70 percent of Americans support this choice and would like to see it enacted in their own States. Recently, in California, which is a State considering a similar measure, 70 percent of Californians across all demographics, all religious groups, all ages, support the idea that incurably ill patients have the right to ask for and receive life-ending medication. I should say that that is the California Compassionate Choices Act that is pending.

Support is found among persons of diverse religious faiths. In the *Oregon v. Gonzales* case, an amicus brief was filed by a religious coalition which advised the Court as follows, quote, “Numerous faiths, religious organizations and religious leaders strongly support physician-assisted dying as an entirely legitimate and moral choice.”

Support is also strong among physicians, with all polling showing a majority of physicians favoring patients being empowered to make this choice for themselves. And all of my written testimony has citation to those studies. Mental health professionals also recognize that dying patients can choose to hasten impending death and be fully mentally competent and, in fact, be acting to preserve sense of self. Again, an amicus brief submitted in the *Gonzales* case details that and I quote that at length in my written testimony.

Although only legal in Oregon, there is a widespread back-alley, underground practice where patients want the freedom to make this choice and they have to turn to the back alley. Many studies document this and many patients and families have spoken of this publicly.

What happens when a patient cannot find a physician who feels safe in discussing this and helping the patient is the patient often acts alone with violent or uncertain means or calls on family members. And there was a dramatic case in Connecticut just this past year exemplifying that. The amicus brief in the *Quill*, *Glucksberg* and *Gonzales* cases of surviving family members speaks to that experience as well—the stories of loved ones who didn’t have access or authority to empower their own decisionmaking at end of life, a very different story than you heard from Julie McMurchie today about a peaceful death at home, in bed, with loved ones present in a peaceful and humane manner.

The question is not whether assisted dying will occur, but rather whether it will occur in a regulated and controlled fashion with safeguards and scrutiny or whether it will occur covertly, in a random, dangerous, unregulated manner.

In conclusion, in the *Glucksberg* and *Quill* cases, the Court recognized that Justice Brandeis’ concept of the States as laboratories was particularly applicable to physician-assisted dying. The Court’s conclusion in those cases that the Federal Constitution does not bar States from prohibiting the practice rested in a reluctance to reach a premature constitutional judgment that would cutoff the process of democratic decisionmaking.

It is timely, prudent and humane for States to enact laws to empower terminally ill, mentally competent adult citizens to control



the timing and manner of their deaths by enabling them to obtain medications from their physicians that could be self-administered to bring about a peaceful and humane death, subject to careful procedures. Passage of such a law harms no one and benefits both the relatively few patients in extremis who make use of such a law and a great many more who draw comfort from knowing this option is available should their dying process become intolerable.

Thank you, Mr. Chairman.

[The prepared statement of Ms. Tucker appears as a submission for the record.]

Chairman BROWNBACK. Thank you, Professor.

Ms. Marker, thank you for joining us.

**STATEMENT OF RITA L. MARKER, EXECUTIVE DIRECTOR,  
INTERNATIONAL TASK FORCE ON EUTHANASIA AND AS-  
SISTED SUICIDE, STEUBENVILLE, OHIO**

Ms. MARKER. Thank you for inviting me to be here today and to testify.

In 1994, Oregon transformed the crime of assisted suicide into a medical treatment when it passed the Death with Dignity Act. In November of 2001, Attorney General John Ashcroft issued an interpretive ruling, known as the Ashcroft Directive, in which he stated that doctors could risk losing their Federal registration to prescribe federally controlled substances if they did so for the purpose of suicide. He based that ruling on the fact that he interpreted prescribing for suicide as being not in the public interest and that such prescribing would not be a legitimate medical purpose under the Controlled Substances Act.

Contrary to widespread misunderstanding, the Ashcroft Directive, if it had been upheld, would not have overturned Oregon's law. Assisted suicide would still have been legal in Oregon. Doctors could still have carried it out. Doctors could still have prescribed any of a number of other prescription drugs that were not federally controlled.

Now, as you have heard, the directive was immediately challenged, and in January of this year the U.S. Supreme Court found that the Attorney General had actually exceeded his authority when he issued his directive. However, that decision was not an endorsement of Oregon's law. It was a very narrow decision and it was based on the fact that the Controlled Substances Act does not explicitly prohibit prescribing for suicide and does not explicitly state that such prescribing of federally controlled substances for suicide is not a legitimate medical purpose. But the Court was clear that if Congress wishes to make such an explicit statement, it can definitely do so by explicit language in the statute. So it is up to Congress to decide.

Now, it helps to examine a bit more what is happening in Oregon, and we do hear about the safeguards. We hear a lot about that. In fact, the Court even referred to some of those safeguards, so why don't I just go over a few of the so-called safeguards that are in the Oregon law.

One is reporting, and that was intended to prevent abuses and to assure that there would be compliance. In the annual reports, it is found that there were 246 reported cases of assisted suicide

in Oregon since it went into effect. However, those numbers may or may not be accurate. As Dr. Katrina Hedberg, who is no opponent of Oregon's law—she was one of the lead authors in most of the official Oregon reports—she had said there is no way to know if additional deaths were reported, and she said that there is no way to know because there is no regulatory authority or resources to ensure compliance with the law.

Likewise, as far as complications, Dr. Hedberg said that not only do we not have the resources to investigate, but we don't have the legal authority to do so. All information in the annual reports, the reports that sound so glowing, actually come from the very doctors who are doing the prescribing. As the State of Oregon said in its first official summary, we just have to assume that doctors are being their usual careful, accurate selves, but we have no way of knowing if the information is accurate or complete.

Then there is the whole requirement that patients be referred for counseling if their judgment is impaired, if the physician believes that to be the case. Well, in fact, in each of the last 3 years, only two patients have been referred for counseling before getting the prescription for the lethal drugs.

But even more importantly, the State of Oregon's Death with Dignity Act refers to what happens when the prescription is written, but there is no requirement that the patient be competent at the time the prescription is filled or taken. And again, as Dr. Hedberg said, the law itself only provides for the writing of the prescription, not what happens afterwards.

A final safeguard that is mentioned is that the patient to be qualified has to have a six-month life expectancy or less. But according to Dr. Peter Rasmussen, who acknowledges having participated in suicide deaths under Oregon's law in the double digits, he said the prognosis is undoubtedly inaccurate. His exact words were that "We can easily be one hundred percent off." He said we could say 6 months, but it could really be 12, but he said I don't think this is a problem. Well, so much for that safeguard.

When you get right down to it, the safeguards are mere illusions. They are about as protective as the emperor's new clothes. So the question is, is it the intent of Congress to have federally issued registrations to prescribe federally controlled substances used in this manner? It is obviously up to Congress.

The CSA can be amended. Congress has never endorsed suicide, as you well know, and went a long way in refusing to facilitate it by passing the Assisted Suicide Funding Restriction Act of 1997. This precludes the use of Federal funding for suicide. It does not prevent using State money for it and, in fact, the State of Oregon uses State money for suicide.

Likewise, Congress can say Federal registrations to prescribe federally controlled substances may not be used for the purpose of suicide. This would indeed leave States to permit doctors to use their medical licenses, which are run by the State, to prescribe other substances.

In closing, I want to just mention a couple of facts about suicide. By the way, suicide, as it is being used here and as I am using it, is just very explicitly meaning the act or instance of taking one's

own life voluntarily or intentionally. That is not emotionally charged or value-laden.

In the United States, in 1999, the Surgeon General actually announced that suicide had become a serious public health problem. As of 2004, there were twice as many suicides per year as homicides in the United States. When Congress last amended the CSA in 1984, it could not have envisioned that it would be considered appropriate to use a Federal registration to prescribe for the purpose of suicide. Congress can easily remedy this and it is up to Congress.

Thank you very much, and I stand ready to assist in any way or answer any questions.

[The prepared statement of Ms. Marker appears as a submission for the record.]

Chairman BROWNBACK. Thanks, Ms. Marker. I appreciate that. Ms. Jackson, thank you for coming.

**STATEMENT OF ANN JACKSON, EXECUTIVE DIRECTOR AND CHIEF EXECUTIVE OFFICER, OREGON HOSPICE ASSOCIATION, PORTLAND, OREGON**

Ms. JACKSON. Yes, thank you very much for inviting me to join you today. I have been Director of the Oregon Hospice Association for the past 18 years. OHA is a charitable public-benefit organization whose goal is to make sure that all Oregonians can have high-quality care, care that is consistent with their personal values when facing a life-threatening illness. I am a co-investigator of research concerning hospice workers' experiences with Oregon's Death with Dignity Act and with hastening death.

In January of this year, the U.S. Supreme Court ruled, as we have mentioned before, that it was the States, not the Justice Department, that have the authority to regulate medical treatment for the terminally ill. OHA was relieved by the Supreme Court's decision, not because we support or oppose the Death with Dignity Act, but because a decision in favor of the Justice Department would have added to the chilling impact that regulatory scrutiny has on pain management, and because a decision against Oregon would have interrupted important research in our laboratories of the States without good reason.

In fact, in the first 8 years, the Act has been very responsibly implemented. None of the predicted dire consequences has occurred. Reports issued by the State of Oregon, as required and supported and augmented by numerous independent studies, are closing a data void. Assisted dying has never before been practiced in a legal environment. We are learning from this wealth of knowledge, applying it to approved end-of-life care in Oregon, and it is knowledge that has application well beyond our borders.

We have learned that physician-assisted dying is not disproportionately selected by those who lack financial resources, health insurance, family support, or education. These individuals tend to be more highly educated, have as much or more social support and adequate financial means. Only two have not had health insurance.

We have learned that assisted dying is not disproportionately used by minorities or the disabled. While fearing pain is a concern, experiencing pain is not a factor. Assisted dying is not used by peo-

ple without access to hospice and palliative care. Every Oregonian has access, even in the most remote and rural areas of the State. Every Oregonian has access to all legal end-of-life options, regardless of who they are or where they live in Oregon.

We have learned that Oregon's hospice workers strongly support a dying Oregonian's right to choose from among all end-of-life options. We have learned how important it is for them to set aside their own needs, as health care professionals must often do, to meet the needs of their patients. We have learned that depression is not an important factor. Hospice workers rank depression and financial concerns among the least important reasons an individual will ask for or use a prescription.

Mental health referrals have declined because physicians routinely refer patients to hospice. Psycho-social and mental status is constantly assessed, addressed and monitored by hospice social workers and the hospice team.

Hospice workers have noted that violent suicide among hospice patients, rare in the past, is virtually non-existent now. Suicide rates in Oregon have always been among the highest in the Nation, but not among the dying at this time. Having health insurance is not an issue. Oregon's hospices provide care without regard to a patient's ability to pay. In addition, hospices can identify at admission individuals as immediately eligible for the Oregon health plan's hospice benefit.

The perspective of hospice workers is important. They visit patients and family caregivers often in the last weeks of life and can compare hospice patients who ask for a prescription with those who do not. Almost all who have used assisted dying have been offered hospice and 90 percent were enrolled.

Patients' physicians identify autonomy, the ability to enjoy life and loss of dignity as primary concerns of those who use assisted dying in Oregon. Hospice workers consistently identify controlling circumstances of death, loss of dignity and the desire to die at home as the most important reasons.

Oregon's home death rate is the highest, its hospital death rate the lowest. Eighty percent of Oregonians have an advance directives and they are followed. When the POLST, physician orders for life-sustaining treatment, is in place, respect for wishes is virtually one hundred percent. The POLST, which was developed in Oregon, is being adopted throughout the country.

Hospice utilization is and has been among the highest in the country. In fact, Oregon was declared the national leader in end-of-life care in 1998, just before the Death with Dignity Act was implemented, and maintains its position as the leader today. It is not true that the quality of hospice and palliative care in Oregon has suffered. Only 246 individuals, not thousands, have ended their lives under provisions of the Act—246 of 240,000 Oregonians who died in the same period.

A study published in 2004 revealed that just 1 of 200 individuals who considers assisted dying and 1 of 25 who makes a formal request will actually use a prescription. Oregon's hospices describe as typical an individual who asks for a prescription on day 1, becomes qualified on day 15, and because he has a plan for his worst fears,

is able to get on with life. That the Oregon law is available, regardless of whether it is used, offers great comfort.

One explanation for the very low rate may be the high quality of hospice and palliative care in Oregon. Oregon's hospices recognized early in the public debate that hospice support, or the lack of it, would be a determining factor in whether a patient would choose to hasten death. Hospice addresses most fears identified by the public as reasons for supporting the legalization of assisted dying.

But autonomy and control, not uncontrolled symptoms, are the reasons people use a prescription. The medical community has not taken such preferences into great consideration in the past. But those are among the few reasons Congress should consider carefully before it takes further action against Oregon. The Oregon Hospice Association would like to think that Congress will consider the potential repercussions on pain management and end-of-life care. Even a proposed law can have an immediate effect of undermining physician willingness to prescribe controlled substances, as we saw in its previous attempts to compromise Oregon's law.

Chairman BROWNBACK. Ms. Jackson, we are going to start wrapping it up. I just want to make sure we get some time—

Ms. JACKSON. Yes, I am.

The Oregon Hospice Association would prefer to think that Congress will recognize and respect the Supreme Court's belief in the value offered in the laboratory of the States.

Thank you.

[The prepared statement of Ms. Jackson appears as a submission for the record.]

Chairman BROWNBACK. Thank you, Ms. Jackson.

Ms. Coleman.

**STATEMENT OF DIANE COLEMAN, PRESIDENT, NOT DEAD YET,  
FOREST PARK, ILLINOIS**

Ms. COLEMAN. Thank you for the opportunity to address the Subcommittee on behalf of Not Dead Yet, a disability rights group that opposes legalization of assisted suicide and euthanasia.

The first thing I want to emphasize is that I am sick and tired of the ways that the culture war has been used to exclude and marginalize the disability community in the public debate on these issues. I am sick and tired of our opponents on the family privacy issue—

[Applause.]

Chairman BROWNBACK. Please, no outbursts. I appreciate people's opinions, and everybody is certainly entitled to that, but let's not have an outburst here.

Ms. Coleman.

Ms. COLEMAN. I am sick and tired of our opponents on the family privacy issue, often our progressive allies on other issues, who talk about the Schiavo case as a conservative travesty and over-simplify the dangers facing people who depend on others for basic needs.

The most common elder guardians are the spouse and adult child, who are also the most common perpetrators of elder abuse. If we were talking about child abuse, everyone would admit that there is a legitimate role for Government intervention, carefully

balanced against privacy rights. Do people in guardianship deserve less?

Nor can we trust State courts as the final word. If we were talking about death penalty, most would admit that the courts are far from infallible and that a right of Federal review is an important protection for the constitutional rights of the accused. Do people in guardianship deserve any less?

I am also sick and tired of our allies on this issue, often our conservative opponents on other issues, who see assisted suicide and euthanasia as violating their principles, but see no contradiction as they slash budgets for the health care we need to survive. This is nothing less than back-door euthanasia.

Assisted suicide is supposedly about terminal illness, not disability. So many question the legitimacy of disability groups meddling and trying to take away what they see as the general public's right to choose assisted suicide. The real issue is the reasons people ask for and doctors give assisted suicide.

Although intractable pain was sold as the primary problem, it is really a bait-and-switch. The reasons doctors actually report are the patient's loss of autonomy, loss of dignity, feelings of being a burden. Unfortunately, popular culture has done virtually nothing to educate the public about how people with severe disabilities actually live autonomous and dignified lives. Our lives are portrayed as tragedies or sensationalized as heroism, but the real-life issues and coping styles that most people will need if they live long enough are left out of the picture. No wonder people who acquire disabilities so often see death as the only viable solution.

Disability concerns are focused on the systemic implications of adding assisted suicide to the list of medical treatment options available to seriously ill and disabled people. The disability rights movement has a long history of healthy skepticism toward medical professionals who are assisted suicide's gatekeepers, which has grown to outright distrust since managed care took over.

But perhaps the most important question is not whether the rights of the few people who request assisted suicide and get it have been compromised, though that is a concern, but whether legalizing these individual assisted suicides has a broader social impact.

Does it matter that a society accepts the disability-related reasons that people give for assisted suicide, declares the suicide rational and provides the lethal means to complete it neatly? Does it harm people who are not deemed eligible for assisted suicide under the current version of the law, but still experience the same sense of loss?

I think we should look at the fact that Oregon has the fourth highest elder suicide rate in the country. In the face of constant social messages that needing help in everyday living or being incontinent robs one of dignity and autonomy, makes one a burden and justifies State-sponsored suicide, maybe Oregon's elders have taken this disgusting and prejudicial message to heart. What looks to some like a choice to die begins to look more like a duty to die to many disability activists.

There is also the problem of doctors as gatekeepers. This week, I received a phone call from a woman with three children. Her ex-

husband, age 35, had been in a car wreck April 2nd. She said that he had been on a ventilator until 2 weeks ago. She described ways in which he seemed to be slowly improving in responsiveness, but from the beginning the doctors had urged the man's mother to withhold treatment. Last week, they finally persuaded her to remove his food and fluids, and he died Sunday. I am getting too many calls like this from people being pressured to withhold treatment.

Another key issue is the problem of State guardians who have an inherent conflict of interest due to the State's role in Medicaid. Now, increasingly another type of third-party medical decision threatens older and disabled people—decisions by physicians in open opposition to the patient, their surrogate or their advance directive; i.e., futility.

A Muslim family from Naperville, Illinois, visited my office recently with detailed records of how family members were pressured to sign a "do not resuscitate" order for their mother. They complained that the ethics committee had no one from their own religion. When they finally refused the DNR, the doctor denied resuscitation anyway and the mother died.

Basically, the bioethicists have warped so-called end-of-life care into life-ending non-care. They have had hundreds of millions of dollars to work with and they have used it to build a guardianship and futile care steamroller that is decimating the civil and constitutional rights of people whose lives are viewed as too marginal or costly to merit support. That is the system in which people are talking about introducing assisted suicide.

While disagreeing with mainstream bioethics, the conservatives have their own way of rationing health care. Instead of rationing based on the person's health status, they ration based on economic status. For those who depend on publicly funded health care, Federal and State budget cuts pose a very large threat. I can't help but note that the power for much of the end-of-life movement has come from the fact that Medicare, including the new Part D, does not cover the primary pain relieving medications, continuing a pattern of extortion—

Chairman BROWNBACK. Ms. Coleman, in all fairness, I need to have you also wrap up, if you could.

Ms. COLEMAN. OK. Regardless of our abilities or disabilities, none of us should feel that we have to die to have dignity or that we have to die to be relieved of pain or that we should die to stop burdening our families or society. Reject the script you have been given by the right to die and the right to life movements. Instead, listen to the disability rights movement. We offer a very different vision, as well as the practical know-how and leadership to build a society and a health care system that respects and welcomes everyone.

[The prepared statement of Ms. Coleman appears as a submission for the record.]

Chairman BROWNBACK. Thank you very much. I want to thank the whole panel. It was a thoughtful set of comments, and a good chiding, too, from Ms. Coleman, and good and appropriate.

Let me pick up on, Ms. Coleman, your comments, and I want to ask just a couple of questions, given where the time is on it, be-

cause I agree with what you are saying about the messages that society sends out. I think those are important. I think the messages that the law sends out are important, as well, and I am concerned about what those do.

I believe that we should message that all life at all stages at all times in all places, no matter who it is, is beautiful and sacred life; that that should be the message coming out. I grow concerned when laws come forward like these that seem to send another message out in the system. OK, it may be true, it may not be true, but I think from what I hear you saying people receive the message as that there is more pressure to die.

Am I correct in hearing what you are saying, and then do you see statistics that then back that up? You cite some in Oregon. Do you see that in other places?

Ms. COLEMAN. There is very little data. In fact, it seems to me that there has not been much research about people requesting to die and what happens as they evolve through their own process of being terminally ill or the processes that people go through in acquiring disabilities. Frankly, we would like to see a lot more research about this end-of-life area than has been conducted. Right now, the causes of death are hidden. The things that doctors say to people are not analyzed in terms of their impact on the decisions people make.

Chairman BROWNBACK. You don't think we know very much about why people in a disability situation die and what is happening surrounding them?

Ms. COLEMAN. Or in a terminal illness situation. I mean, most people who are terminal go through phases of disability before they get there and that is a source of great concern to us because we see people trying to say, well, there is some fundamental difference between the terminally ill and the disabled, and that is not the case at all. Terminally ill people are a subset of people with disabilities.

The issues that they are raising about the concerns they face are the same as disability issues, that sense of being a burden on family if there is not enough home and community-based services or other services to make it practical. And that burden feeling is a source of great concern. We are all in favor of the implementation of the U.S. Supreme Court decision in Olmstead which would give consumers a choice in long-term care, and that is not happening yet in most States. Those choices are not there and many people are forced into institutions where they pretty much say, well, I would rather die than go to a nursing home. That could be considered understandable, but we are really trying to push for much better options that give people the kind of support they need and are not forcing them into situations where they feel like a burden on family.

Chairman BROWNBACK. Let me ask Mr. Smith, if I could, I ran across statistics and held a hearing on it a year ago—Senator Kennedy and I have a bill addressing it—on the percent of children diagnosed with Down's syndrome in utero that are aborted. We are at nearly 90 percent now of children in the United States diagnosed in utero with Down's syndrome that are then aborted.



Senator Kennedy and I have a bill. We are obviously on different sides in the abortion issue, but both of us feel like that number is just way too high. And it is very troubling that you would get somebody that has Down's syndrome—if they get here, feet on the ground, they are protected and we try to work with the situation with the Americans With Disabilities Act. But if you are in the womb, you are disproportionately killed. It is one of those things that you look at and you say, OK, is that an unintended consequence of saying, OK, this is the right to choose, this is where we are?

I don't like it, I don't agree with it, period, that this is taking place, and yet it almost seems to be a product of, OK, we have got a right to choice in 1973, in Roe. Then the science further develops and we can determine the information better. We are going to be able to do soon over a hundred tests in utero for what the child looks like, or features.

These sorts of unintended consequences when you start down a path—it seems like to me we have seen one there and you have got a similar path you could argue we may well be looking at in this feature; that we don't know in 20, 30 years where we end up if you open this door and what technology will drive you to at that point in time.

Have you seen papers? Are there people who have written on this topic that you look at and you say, OK, this is a reasonable place we would be in 30 years if we opened this door, or given the technology trends that we have, given the change of law that this would be?

Mr. SMITH. Yes, I have, actually. It strikes me that what you are describing is a return of eugenics thinking, and that is a subset of a belief that human life does not have intrinsic value simply and merely because it is human. I remember once giving a speech to a medical school in which I proposed that we have to look, especially medical professionals, at each human being as having equal human dignity. That is the fundamental basis of universal human rights.

I had a bright young medical student come up to me afterwards and he said, you know, I am involved in genetic counseling. What am I supposed to tell people when a woman presents having tested to have a baby who is Down's? And I said, well, why don't you bring in a Down's family and let the family and the Down's human being present their own story instead of seeming to push in a certain direction?

I think the spread of the idea that there are some lives not worth living is already happening in Belgium, which has only legalized assisted suicide and euthanasia for a couple of years. The very first person who was killed by euthanasia violated the Belgian guidelines. It was a patient with multiple sclerosis, and nothing, of course, was done about it.

In Flanders, they have done studies where infanticide is raising to the levels already of Dutch proportions. In the Netherlands, the day the—in fact, I have it with me—the day the Dutch formally legalized euthanasia—the very next day, the Dutch Minister of Health said we have to have suicide pills for elderly people who are

tired of life, because this creates a mind set that begins to see death as an acceptable answer to human suffering.

In Oregon, it has not been problem-free. In fact, I think it would be a tremendous benefit to the country if the Congress at some point did a detailed investigation. And because of time, I will only talk about one issue. It is the issue of what I call doctor-shopping. Let's assume I am a patient who wants assisted suicide and I go to my doctor and I request the lethal prescription and my doctor says no. My doctor says, you know what, I am not sure you are going to die within six months, or, you know what, I think there are things we can do that would help you not want to kill yourself.

I then just go off and go to an assisted suicide advocacy organization and they refer me to a doctor, often Dr. Rasmussen, who facilitates a lot of these assisted suicides. And if I meet the criteria for the law, I will get the lethal prescription. In my view, that is Kevorkianism. That is not as it is sold that it is going to be just an intimate decision with a long-time family doctor who knows your values, and so forth. It is not necessarily happening that way.

In the first couple of years of the statistics that were published, you saw that some patients died from assisted suicide after only knowing the prescribing doctor for 2 weeks or less. And the responsive organ to the people such as myself who raised a concern about that was to keep tracking that statistic. They just stopped tracking it.

So there is a lot going on in Oregon that I think could use a real thorough exploration rather than the facile kinds of statistics we get based mainly on information provided by the lethally prescribing doctors who are about as much as likely to tell the State they violated the laws as they are to tell the IRS they cheated on their taxes.

Chairman BROWNBACK. I want to get, if I could, Professor Tucker, a question to you on this point. You are very accomplished and you have worked on this area a lot in the legal field, but I want to take you, if I can, to another area. You may feel like you are just not competent to address it because it is a numbers and it is the trend lines; it is not the legal issue.

In 1973, we had—this is according to CDC numbers—just over 615,000 abortions in the United States. In 1990, we were at 1.4 million, more than double. Then several years ago, President Clinton, when he vetoed the partial birth abortion ban, was saying we want abortions in the United States to be safe, legal and rare. And a lot of people were saying, OK, I like that idea; I want it to be safe, I want it to be legal, I want it to be rare. I don't think you can argue it is rare. We may be able to argue the other points.

But I take you to the debate you are in right now on this particular issue, and you may not want to answer this because it is where does the trend line take us to. And I think you would want assisted suicide to be safe, legal and rare.

Ms. TUCKER. Indeed.

Chairman BROWNBACK. But the trend lines of these sorts of things don't appear to go that way once you open these issues up on the projections of it. I mean, the trend line seems to be it opens in one area and then it really expands substantially to where you

could have it as safe and legal, but certainly not in the rare category, and it expands into a whole series of fields.

I am sure you have thought about that and I would appreciate your thought on that subject.

Ms. TUCKER. I think that in Oregon it is, in fact, quite rare. The deaths in Oregon have not exceeded 30 per year. It started out with fewer per year. Ms. Jackson has, I am sure, the details in the forefront of her mind, but it stayed very rare.

An interesting aspect in Oregon, however, is that more patients every year start the process, go through the process, obtain the medications, than go on to take them. And patients are comforted by knowing that they have this option, and few of them actually go on to take the medications.

And I should say I hear a lot of concern about are we starting down a dangerous road. Oregon's law is only about patient self-administration of medication. So these stories that we have heard about the Netherlands where physicians are euthanizing patients are not at all on the table in Oregon or any other State here. The support in the United States among the American people is for patient self-administration.

The Netherlands has always permitted euthanasia—different culture, different choice. In this culture, the public support is for patient self-administration. So that is where the line is drawn. It has been rarely used in Oregon, with safeguards that hold that line very well indeed.

Chairman BROWNBACK. And you don't buy this messaging that we are doing to people and that this has an impact on them, or that once you start down these roads, the likelihood of substantial expansion that we have seen in other countries that have gone—you just don't think that applies here?

Ms. TUCKER. No, because no one races to make this decision. As you heard from Julie McMurchie's story, her mother, upon receiving the diagnosis of cancer, went through extensive curative therapy. There is surgery, there is radiation, there is chemotherapy, there is palliative care. Patients who receive these diagnoses want to access as much curative and palliative care as possible. They pursue that aggressively.

But for some, they come to a point where the illness has ravaged their bodies so tremendously and they have so lost their ability to bear this cumulative burden that they choose to have a peaceful, comfortable death. It is not a question about life versus death. It is a question about a horrific death that is prolonged beyond endurance and a death that is peaceful and on their own terms. And those people love life. Those are culture of life people. They love their life and they want that life to come to a peaceful closure.

Chairman BROWNBACK. Well, it is a very good, well-spoken, well-thought panel. I appreciate it, and I am sure it won't be the last time that the topic is visited.

We will keep the record open for the requisite number of days. We will accept Senator Feingold's statement into the record, if he cares to submit one. I know he would have liked to have been here, but he is carrying an amendment on the floor.

I do hope the panelists here and maybe those who watched will think about these topics. I do think it is important that we con-

sider, when you enter, where it is that you exit on these massive policy issues. You know the lawyer's statement of good facts make bad law. You can look at a situation and say that is just—I mean, factually you look at it and you say this is terrible.

But then once you consider entering into it and you expand into it, which is the logical way that these things happen—that has been the history of our country and of mankind that I have seen—they have consequences as you move on down. I hope people can consider that and I hope we will get some good written statements.

I particularly want to thank Ms. Coleman. I thought you had really an interesting and a good thought, and it was a good reminder of some of the things we need to look at.

The hearing is adjourned.

[Whereupon, at 2:49 p.m., the Subcommittee was adjourned.]

[Questions and answers and submissions for the record follow.]

## QUESTIONS AND ANSWERS

### Senate Subcommittee on the Constitution Hearing on “The Consequences of Legalized Assisted Suicide and Euthanasia”

#### Questions for the Record from Senator Russ Feingold

##### Questions for Ann Jackson:

- 1) Senator Brownback expressed concern about the larger issue of suicide and depression, and whether individuals are choosing physician-assisted dying for appropriate reasons. You spoke of Oregon as a leader in end-of-life care totally apart from the Death with Dignity Act, including having a very effective hospice infrastructure and increasing education efforts so that 80% of Oregonians have end of life directives. To what extent do you believe that these factors are important to Oregon’s statute working as intended? What surrounding factors, whether it is effective Medicare as Dr. Coleman points out, or a well-funded hospice system, do you think are essential to a viable system of physician assisted dying?

I believe that having a strong statewide hospice infrastructure and a medical community that strongly values end-of-life planning has played a significant role in the successful implementation of Oregon’s Death With Dignity Act (ODDA). I am using the word “successful” to describe an implementation process that has consistently avoided and averted the many bad outcomes predicted during the public debates in Oregon. While Oregon was a leader in end of life care before the ODDA became law—among the states with the highest hospice penetration and highest utilization of advance directives—hospice workers agree, whether they support or oppose the concept of physician assisted dying, that it is easier now to have open and honest and meaningful conversations about care at the end of life. Ironically, it is those people who ask about the ODDA—people who personally direct their care—who are referred to hospice earliest in the dying process and who benefit most from hospice. While every Oregonian has access to hospice care, conversations about hospice may be delayed if the patient waits for the doctor to tell them and the doctor waits for the patient to ask. When hospice is involved, there is no reason for any American to die in pain, in hospitals hooked up to machines keeping them alive, alone, while burdening their caregivers and impoverishing their families. When hospice is involved, hospice social workers assess and the hospice team monitors and manages the psychosocial well-being of every hospice patient, including concerns about suicide and depression. People who use the ODDA use it for reasons of autonomy, not for the reasons generally given for believing the option should be legal.

And, I strongly believe that Dr. Coleman is correct, when she points out that Medicare and Medicaid do not adequately meet the needs of many Americans, and certainly the disabled population is among them. I think that a well-funded health care system is essential and long overdue.

I also think that a well-funded hospice system would be an important component in assuring a responsible system of physician-assisted dying, but I would like to point out

that Oregon's hospice system under Medicare is among the lowest-funded in the United States. Yet the quality of end of life care in Oregon is ranked very high, costs very little, and includes physician-assisted dying, an option that is rarely used. When the bulk of Medicare and Medicaid dollars are spent in the last year of life, Oregon's experience suggests that a sensible system of universal health care in the United States may be far more possible than is conventionally believed.

- 2) Senator Wyden spoke about the potentially negative effect of federal involvement in this area of medical practice, especially if Attorney General Ashcroft's "no legitimate medical purpose" interpretation of the Controlled Substances Act had been upheld. What impact do you think federal restrictions would have on innovative efforts by the states, by individual doctors, and non-profit organizations such as yours? Do you think there is an appropriate federal role in this area?

The chilling impact of regulatory scrutiny on physician willingness to prescribe opioid medications is well established. Every time Oregon has been threatened by the federal government or Congress since 1997, hospices have documented incidents where pain medications were decreased or withheld—sometimes by a well-meaning family member rather than a doctor. It's easier and more acceptable to "just say no", than it is to say "yes". Physicians, if they are challenged for prescribing too much, risk their livelihoods. It should be noted that physicians whose patients are enrolled in hospice have the support of the hospice team, when prescribing for pain management, but physicians acting alone are vulnerable.

I think that the Controlled Substances Act is ineffective. I think that its costs outweigh its benefits. I think that there is an appropriate federal role in this area, but adding federal restrictions would be counterproductive.

- 3) Please reflect on the testimony of the opponents of the Oregon law that you heard at the hearing or other criticisms of which you are aware. Are there any provisions in the Oregon law that you would change? Is there any extra data that you would collect, or further requirements on patients or doctors that you would impose?

I was present at the hearing, not as a proponent, but as the spokesperson for the Oregon Hospice Association, an organization that has taken no position on the Death With Dignity Act, representing an industry that has had direct experience with 86 percent of those individuals who have ended their lives by ingesting medication as provided under the Act. For each of the individuals who have ingested medication, there are 199 Oregonians who have considered using the Act. A large majority of those individuals, too, have been cared for by Oregon's hospices. I am a co-investigator of many IRB-approved research projects on this issue.

I found the testimony of the opponents almost totally unfounded by the facts of my personal and professional experience.

I have frequently reviewed the provisions of the Death With Dignity Act. If I were to change anything, it would be to change the term "terminal illness" to "terminal illness or condition". I have also been alarmed at safeguards added to other proposed laws that would, in my opinion, restrict arbitrarily and unnecessarily access to the Act. Academically, I appreciated the optional data that was included by the State of Oregon in its first reports, but I recognize that the costs of including more information are prohibitive. The additional information was more of interest than of necessity. It's important to note that the State of Oregon's Health Division is not alone in collecting data. Independent investigators are adding and verifying data in Oregon's laboratory of the states, as well.

I would impose no additional requirements on patients or doctors, including psychological or psychiatric evaluations. I would, however, impose higher standards on hospice psychosocial assessments and monitoring for all individuals enrolled in hospice. Quality assurance performance indicators (QAPI) being developed to comply with the Medicare Hospice Benefit's new conditions of participation (COPs) include such standards.

**Senate Subcommittee on the Constitution**  
**Hearing on "The Consequences of Legalized Assisted Suicide and Euthanasia"**

**Questions for the Record from Senator Russ Feingold**

**Questions for Julie McMurchie:**

- 1) You discussed briefly with Senator Brownback the very important question of the words we choose to use in this so-called "right to die" debate. There clearly seems to be disagreement in this discussion over the use of the word "suicide" to describe the decision of a terminally ill patient to make use of the Oregon law. Please elaborate on how you feel about the term "physician-assisted suicide"?

It is clear that the word "suicide" has negative connotations. There is no other situation where that term can be used that does not imply a person is depressed and chooses to kill him or herself to avoid living what could be a very long life. People that take advantage of Oregon's Death with Dignity law have a clear picture and timeline of their death. They will never get "better". My mother had spent 6 weeks in bed, working with hospice and pain specialists to get to a point where she could even sit up. She had tumors growing in her airways that ran the risk of rupturing, which would have caused immediate and traumatic death. She had lost control of her bowels. What my mom chose was to die at a time when she could have her children with her. She hastened her imminent death, she did not commit suicide.

- 2) In his testimony, Wesley Smith expressed the concern that terminally ill patients who decide to end their life may be unduly influenced by their physician or, alternatively, by family members who "desire to be free from the burden of caring for the patient." Did you worry about such influences when your mother made this decision? How could you be sure that she was making a personal choice, free of influence by others?

My mother had approached her death very straightforwardly from the time she was first diagnosed with lung cancer. She lived a very full life until she was no longer physically able to engage in the activities that brought her satisfaction. I was her main caregiver, and I begged her to live with me during her illness. She would have none of that. She knew she was going to die, and she wanted to do it on her own terms. Using Oregon's law was her idea, she was the one to bring it up. Much of the sadness that she felt during her illness was the pain that she knew her children would feel upon her death. I wanted her to live, she knew that. Her decision was so consistent with her personality, and the way she confronted her illness and impending death. There was no chance that anyone influenced her.



- 3) Your mother and her physician had to follow the requirements of the Oregon law. I wanted to get your personal perspective on the safeguards in that law. Were there any requirements that you thought were especially difficult or unnecessary, or on the other hand too lax? Would you have wanted a shorter or longer waiting period, or greater flexibility for number of doctors and witnesses needed? Were there any provisions that seemed ripe for abuse?

I think the law is very well designed. I have since worked with many families who have used the law, and I think the safeguards are structured well. I am a proponent of all the waiting periods, and I think two physicians is a good idea. Unfortunately, it is often very difficult to get two physicians to participate, especially, as is often the case, if the patient has limited mobility, resources for travel, and/or lives in a rural area. I wouldn't change a thing with the requirements.

**Senate Subcommittee on the Constitution**  
**Hearing on “The Consequences of Legalized Assisted Suicide and Euthanasia”**

**Questions for the Record from Senator Russ Feingold**

**Questions for Kathryn Tucker:**

1. One of Senator Brownback’s major concerns seems to be the possibility of a “slippery slope” – that Oregon’s currently successful law will be transformed into a system of active euthanasia, with a significant risk that euthanasia will take place without patient consent. Even if a careful law is passed today, critics worry that legislators may have a more casual attitude a decade from now and might pass legislation that lacks the safeguards of the Oregon law, or state officials might fail to enforce those safeguards. Oregon’s experience is now approximately eight years old. Do you believe these concerns are justified? What safeguards in the Oregon law do you believe are essential to preventing such a slippery slope from occurring? Does the experience in the Netherlands have lessons from which states adopting an Oregon-like law should learn?

I don’t believe these concerns are justified, and the evidence supports my position. Careful studies of both Netherlands and Oregon show no evidence of a “slippery slope.” The Battin/Ganzin study done in 2007 examines this.

The Death with Dignity Act (DWDA) requires healthcare providers to file reports with the state documenting their actions, which means that there is extensive documentation of Oregon’s experience. To date, the Oregon Public Health Division and Department and Human Services have issued nine annual reports that present and evaluate the state’s experience with the DWDA. These reports constitute the only source of reliable data regarding actual experience with legal, regulated physician-assisted dying in America. The findings have shown that the use of physician-assisted dying has been limited. During the first nine years in which physician-assisted dying was a legal option, only 292 Oregonians chose it. And although there has been a gradual increase in the rate of those opting for physician assisted-dying, the overall rate remains low: the 38 terminally ill adults who chose this option in 2005 represented only 12 deaths for every 10,000 Oregonians who died that year. A 2000 survey of Oregon physicians found that they granted 1 in 6 requests for aid in dying, and that only 1 in 10 requests resulted in hastened death. Roughly one-third of those patients who complete the process of seeking medications under the DWDA do not go on to consume the medications. These individuals derive comfort from having the option to control the time of death yet ultimately die of their disease without exercising the control.

Moreover, 14 years after Oregon passed its law in 1994, Washington passed a virtually identical measure in 2008, with no relaxation of the strict requirements for eligibility or exercise of this option.

2. There seems to be a real disagreement between your assessment of the quality of Oregon’s safeguards and some of the other panelists. Wesley Smith spoke of ‘doctor shopping’ to allow

patients who might not have a terminal illness or meet other requirements to circumvent the regulations. Rita Marker suggested that there is substantial under-reporting by physicians in Oregon in dubious cases, and the law provides no infrastructure for investigations of such discrepancies. Can you assess these criticisms and discuss what you believe to be the strengths and weaknesses of the safeguards in Oregon's physician-assisted dying law?

Oregon's Death with Dignity Act establishes tightly controlled procedures under which competent, terminally ill adults who are under the care of an attending physician may obtain a prescription for medication to allow them to control the time, place, and manner of their own impending death. The attending physician must, among other things, determine that the patient is mentally competent and an Oregon resident, and confirm the patient's diagnosis and prognosis. To qualify as "terminally ill," a person must have "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months." The attending physician also must inform persons requesting such medication of their diagnosis and prognosis, the risks, the probable results and the alternatives to taking the medication, including, but not limited to, hospice care and pain relief. A consulting physician must confirm the attending physician's medical opinion.

Once the request from the qualifying patient has been properly documented and witnessed, and all waiting periods have expired, the attending physician may prescribe, but not administer, medication to enable the patient to end his or her life in a humane and dignified manner.

The annual reports referenced above, show that vulnerable populations have not been placed at risk by the implementation of the Oregon law. Some have voiced concerns about disproportionate use of this option by the elderly, women, the uninsured, people with low educational status, the poor and the disabled. However, researchers who have examined the experience in Oregon have concluded that there is no evidence to suggest that these concerns were well founded. The data demonstrates that the option of physician-assisted dying has not been forced upon those who are poor, uneducated, uninsured or otherwise disadvantaged. For example, the eighth annual report found that a higher level of education is strongly associated with the use of physician-assisted dying; those with baccalaureate degree or higher were 7.9 times more likely than those without a high school diploma to choose physician-assisted dying. The report found that 100% of patients opting for physician-assisted dying under the DWDA had either private health insurance, Medicare, or Medicaid, and 92% were enrolled in hospice care. Leading scholars have come to conclusions such as this: "I worried about people being pressured to do this [...] but this data confirms [...] that the policy in Oregon is working. There is no evidence of abuse or coercion, or misuse of the policy." Additionally, researchers who have examined the Oregon data have reported that there is "no evidence of heightened risk" for people with nonterminal physical disabilities. The Executive Director of the Oregon Advocacy Center (OAC), which provides legal advocacy for individuals with mental and physical disabilities throughout Oregon and is mandated by law to investigate complaints of abuse or neglect of individuals with disabilities, including inappropriate actions taken to hasten the death of such an individual, has stated

under oath that OAC “has never received a complaint that a person with disabilities was coerced to make use of the Dignity Act.” The only complaints that OAC had received, he said, were a few expressing concern that some persons who wish to make use of the Act might be prevented by their physical disabilities from self-administering medication as permitted under the Act.

Not only have the harms some feared failed to materialize, but the DWDA has produced distinct benefits. First, the DWDA has galvanized significant improvements in the care of the dying in Oregon. Oregon doctors report that since the passage of the Dignity Act, steps have been taken to improve their ability to provide adequate end-of-life care. These efforts include improving their knowledge of the use of pain medications for the terminally ill, improving their ability to recognize depression and other psychiatric disorders, and more frequently referring their patients to hospice programs. In addition to the improvement of end-of-life care, the legal option of physician-assisted death has psychological benefits for both the terminally ill and the healthy. The availability of the option of aid in dying gives the terminally ill autonomy, control and choice, which physicians in Oregon have identified as the overwhelming motivational factor behind the decision to request assistance in dying. Healthy Oregonians know that if they ever face a terminal illness, they will have control and choice over their manner of death.

3. Within the larger framework of ‘dignity,’ it seems that a number of different justifications are given for allowing patients to choose physician-assisted death. Julie McMurchie spoke of her mother’s desire to have control and to be able to be surrounded by her family at death. Ann Jackson spoke of similar desires. Your testimony focused on patients wanting to end a prolonged dying process marked by extreme suffering and deterioration. A number of opponents of Oregon’s law have suggested that motivations unrelated to pain should not be considered valid justifications for an early termination of life. What do you believe are justifiable reasons for a terminal patient to choose physician-assisted dying? Does the state have any interest at all in assessing the patient’s reason for wanting to die?

When the patient finds the process intolerable, we know from the data collected and reported from Oregon that patients choose aid in dying for a variety of reasons, typically no one reason dominates the decision. Patients find the cumulative burden of the final stages of terminal illness – including pain, suffering, distressing symptoms, extreme fatigue, nausea, breathlessness, progressive and inexorable deterioration of bodily function and integrity – to be more than they can or want to endure.

The state’s role ought to be limited to ensuring that a patient’s request is informed, voluntary and enduring, and is made by an individual competent to make health care decisions for him or herself.

SUBMISSIONS FOR THE RECORD

Testimony Before the  
United States Senate Judiciary Subcommittee  
On the Constitution, Civil Rights and Property Rights

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## Introduction

### Personal History

Mr. Chairman, Vice-Chairman, members, thank you for the opportunity to address this Subcommittee. My name is Diane Coleman. I have a Juris Doctorate and Masters in Business Administration from the University of California at Los Angeles, and am a member of the California bar, on inactive status. During the last twenty-four years, I have been employed first as an attorney for the State of California, then as Co-Director of an assistive technology center in Nashville, Tennessee, and now I am the Executive Director of Progress Center for Independent Living in Forest Park, Illinois, a nonprofit nonresidential service and advocacy center operated by and for people with disabilities.

I have had a neuromuscular disability since birth, and have used a motorized wheelchair since the age of eleven. From 1987 through 1995, I volunteered as a national organizer for ADAPT, also known as the American Disabled for Attendant Programs Today. I continue to advocate, speak and guest lecture on long-term care issues within Illinois.

When I was six years old, my doctor told my parents that I would not live past the age of 12. A few years later, the diagnosis changed and so did my life expectancy. Over time, I learned that respiratory issues would probably develop. I have friends who've used nighttime ventilators for years, so I knew what symptoms to watch for, and four years ago, started using a breathing machine at night. I had two other friends, one in her 30's and one in her 50's, who needed the same thing. But their doctors discouraged them from it, reinforcing their fears, and either didn't know or didn't disclose what the medical journals said would happen as a result. At an early age, they each went into respiratory distress, and died within a month from infections. A number of my other friends have been pressured by hospital employees to sign do-not-resuscitate orders and other advance directives to forego treatment, coupled with negative statements about how bad it would be if they became more disabled. Frankly, I'm becoming worried about what might happen to me in a hospital if I have a heart attack or other medical crisis. I have appointed my health care proxy, but will the decisions I have entrusted to him be followed by my health care providers? I am not at all convinced that decisions to live are any longer treated with the same respect by health care providers as decisions to die. In fact, I am sure they are not.

### Not Dead Yet

Ten years ago, I was on my way to testify before the House Constitution Subcommittee about the opposition to legalized assisted suicide coming from national disability rights organizations. Many of us were worried about Jack Kevorkian, whose body count was 70% people with non-terminal disabilities, and we were worried about two Circuit Courts declaring assisted suicide a constitutional right. Kevorkian even had a legal defense fund provided by the Hemlock Society, later renamed "End-of-Life Choices" and now merged with "Compassion in Dying" to form "Compassion and Choices." In 1996, disability

activists had begun to think that we needed a street action group like ADAPT to address the problem (see [www.adapt.org](http://www.adapt.org)), and it was actually the head of ADAPT, Bob Kafka, who thought of our name, taken from a running gag in Monty Python and The Holy Grail, "Not Dead Yet." From our viewpoint, assisted suicide laws would create a dangerous double standard for society's response to suicidal expressions, an unequal response depending on one's health or disability status, with physicians as gatekeepers. That sounds like deadly discrimination to us and, frankly, we've been disappointed that the U.S. Dept. of Justice didn't use our civil rights law, the Americans With Disabilities Act, instead of the Controlled Substances Act, to challenge the Oregon assisted suicide law. Like other minority groups, we feel that discrimination is best addressed on the federal level, and states rights have too often meant states wrongs.

### **The Problem of the Culture War**

The first thing I want to emphasize is that I'm sick and tired of the hypocrisy on both sides of the culture war in this debate.

During the primary election campaigns this year, I still heard of candidates using the Schiavo case to fuel the culture war. My personal hero during that crisis has been conveniently forgotten. Senator Tom Harkin raised the legitimate concerns of people with disabilities. In a press conference held on March 18, 2005, he said:

*Where there is a genuine dispute as to what the desires of the incapacitated person really are, then there ought to be at the end some review by a federal court outside of state jurisdiction. You might say, 'Why a federal court?' State courts vary in their evidentiary proceedings and in their process -- fifty different ones. . . . Every review of that, up through the state courts, is basically on the procedure, not upon the first facts. In a case like this, where someone is incapacitated and their life support can be taken away, it seems to me that it is appropriate -- where there is a dispute, as there is in this case -- that a federal court come in, like we do in habeas corpus situations, and review it and make another determination.*

I'm sick and tired of our opponents on this issue, often our liberal or progressive allies on other issues, who over simplify the dangers facing disabled people who depend on others for basic needs. Court appointed and statutory guardians have potential conflicts of interest. The most common are the spouse and adult child, who are also the most common perpetrators of elder abuse. If we were talking about child abuse, everyone would admit that there is a legitimate role for government intervention, carefully balanced against privacy rights. Do people in guardianship deserve less? Nor can we trust state courts as the final word. If we were talking about death penalty cases, most would admit that the courts are far from infallible, and that a right of federal review is an important protection for the constitutional rights of the accused. Do people in guardianship deserve less?

I'm also sick and tired of our allies on this issue, often our conservative opponents on other issues, who see assisted suicide and euthanasia as violating their principles, but see

no contradiction as they slash budgets for the health care we need to survive. The Republican Governor of Missouri has cut Medicaid funding for feeding tubes and ventilators, establishing a difficult procedure to get these devices, with most who try to use it reportedly failing to get what they need. Jeb Bush just cut Medicaid coverage for the food that goes in the feeding tube by adding similar burdensome procedures. The irony is not lost on us, but media exposure in Florida put this action on hold. This is nothing less than back door euthanasia. And let's face it, much of the struggle at the state level flows from federal cuts. Back door euthanasia.

Disability rights groups have a unique perspective, informed by both our principles and our experiences. Our principles embrace non-discrimination, civil rights and self-determination. Our collective experiences include monumental struggles against the crushing oppression of a health care system that devalues us and a society that fears significant disability as a fate worse than death. We are consumers on the front lines of the health care system, facing your worst fears with grace and dignity, yet we have been pushed to the margins and even excluded outright from the debate on these issues.

I am sick and tired of our opponents who claim that Not Dead Yet represents only a few. Twenty six national disability groups strongly questioned the use of conflicted evidence to justify Terri Schiavo's euthanasia by starvation and dehydration. Since then, thirty-seven organizations have adopted a Statement of Common Principles,<sup>1</sup> affirming the civil and constitutional rights of people with disabilities, whatever our age or type of disability, but especially those under the decision-making authority of a third party.

I am even more sick and tired of our opponents who falsely claim that Not Dead Yet is a puppet of the Christian right, or funded by pro-life groups (which our bylaws prohibit). One blogger, *Working For Change* columnist Bill Berkowitz, recently claimed that our attorneys on our three Schiavo amicus briefs were "foot soldiers" of the religious right and funded by conservative foundations.<sup>2</sup> But our attorneys never received a penny for their services on behalf of Not Dead Yet and the 16 national disability rights groups that joined our briefs, and these attorneys work for a prominent disability rights organization in Chicago, Access Living.

Why are our opponents so intent on misleading people about who we are? Perhaps they think that is the best way to stop people from hearing what we have to say. We will never be silenced. But who will question the simplistic rhetoric and decide to listen?

The topic of this hearing is broad, and could include five areas of concern to us: assisted suicide, passive euthanasia based on a surrogate's decision to withhold treatment, passive euthanasia based on a physician's decision to withhold treatment (aka futility judgments), active euthanasia, and denial of health care by a health plan or government insurer (aka back door euthanasia).



### Assisted Suicide

#### What's It Got To Do With Disability?

Assisted suicide is supposedly about terminal illness, not disability, so many question the legitimacy of disability groups "meddling" and trying to "take away" what they see as the general public's right to choose assisted suicide, some say when they're terminally ill, others say when they're suffering. The stated criteria vary between Compassion and Choices and Final Exit Network, among others, and some people switch group affiliations and eligibility criteria depending on the audience.

The disability experience is that people who are labeled "terminal," based on a medical prediction that they will die within six months, are -- or will become -- disabled.

The real issue is the reasons people ask for assisted suicide. Although intractable pain has been sold as the primary reason for enacting assisted suicide laws, it's really a "bait-and-switch" situation. The reasons doctors actually report for issuing lethal prescriptions are the patient's "loss of autonomy," "loss of dignity" and "feelings of being a burden."

Those feelings often arise when a person acquires physical impairments that necessitate relying on other people for help in tasks and activities formerly carried out alone. Those are disability issues. In a society that prizes physical ability and stigmatizes impairments, it's no surprise that previously able-bodied people equate disability with loss of dignity.

Studies of patient attitudes toward assisted suicide and euthanasia confirm that "[p]atients' interest in physician-assisted suicide appeared to be more a function of psychological distress and social factors than physical factors."<sup>3</sup> "When patients ask for death to be hastened," another study concluded, "the following areas should be explored: the adequacy of symptom control; difficulties in the patient's relationships with family, friends, and health workers; psychological disturbances, especially grief, depression, anxiety, . . ."<sup>4</sup> And another study exploring psycho-social factors provided the following analysis:

*The desire for euthanasia or assisted suicide resulted from fear and experience of two main factors: disintegration and loss of community. These factors combined to give participants a perception of loss of self. . . . Symptoms and loss of function can give rise to dependency on others, a situation that was widely perceived as intolerable for participants: "I'm inconveniencing, I'm still inconveniencing other people who look after me and stuff like that. I don't want to be like that. I wouldn't enjoy it, I wouldn't, I wouldn't. No, I'd rather die."*

*Participants frequently used the notion of dignity to describe the experiences associated with disintegration: . . . "You've become a bag of potatoes to be moved from spot to spot, to be rushed back and forth from the hospital, to be carried to your doctors' appointments or wheeled in a*

*wheelchair, and it really does take away any self-worth, any dignity, or any will to continue to live."*

*. . . Loss of community entailed the progressive diminishment of desire and opportunities to initiate and maintain close personal relationships, owing to loss of mobility, exclusion and alienation by others, and self-isolating actions by participants. . .*

*Participant: "I think we should all be allowed to die with our dignity intact."*

*Interviewer: "OK and what do you mean by dignity?"*

*Participant: "Um, the ability to perform simple things like, you know, going to the bathroom on your own and not through a bag, um, breathing with your own lungs, . . . I used to be somebody, but now, like I mean, you know, I'm no better than like a doll, somebody has to dress me and feed me and I guess it's uh, I don't know how to explain it, really."<sup>5</sup>*

These are common words for newly disabled people.

Disability groups, however, object to the implicit claim that any of us need to die to have dignity. Needing help in dressing, bathing and other intimate daily tasks does not rob a person of autonomy and dignity. Unfortunately, popular culture has done virtually nothing to educate the public about how people with severe disabilities actually live autonomous and dignified lives. Our lives are portrayed as tragedies or sensationalized as heroism, but the real life issues and coping styles that most people will need if they live long enough are left out of the picture. No wonder people who acquire disabilities so often see death as the only viable solution.

But studies show that whether or not they are terminally ill, people who ask for assisted suicide or euthanasia usually change their minds.<sup>6</sup>

#### The Problem of Physicians as Gatekeepers of Assisted Suicide

The disability rights movement has a long history of healthy skepticism toward medical professionals, and there's an established body of research demonstrating that physicians underrate the quality of life of people with disabilities compared with our own assessments.<sup>7</sup> Our skepticism has grown into outright distrust in our profit-driven health care system.

It should be noted that suicide, as a solitary act, is not illegal in any state. Disability concerns are focused on the systemic implications of adding *assisted* suicide to the list of "medical treatment options" available to seriously ill and disabled people. The Oregon Law grants civil and criminal immunity to physicians providing lethal prescriptions based on a stated claim of "good faith" belief that the person was terminal, acting voluntarily, and that other statutory criteria were met. This is the lowest culpability standard possible,

even below that of "negligence," which is the minimum standard theoretically governing other physician duties.

As the Oregon Reports on physician-assisted suicide make clear, the state has not been able to assess the extent of non-reporting or noncompliance with the law's purported safeguards, but only obtains brief interviews with physicians who file their paperwork. There are no enforcement provisions in the law, and the reports themselves demonstrate that non-terminal people are receiving lethal prescriptions.<sup>8</sup> As the *Oregonian* newspaper stated on March 8, 2005 in "Living with the dying 'experiment,'" examining the case of David E. Prueitt who woke from his assisted suicide after two weeks and did not try again, "The rest of us . . . still need an answer from a system that seems rigged to avoid finding one."

This is the system that controls eligibility for assisted suicide under the Oregon law. Physicians decide who's terminal and who isn't, despite well-known problems with prediction. Physicians decide what "feasible alternatives" to disclose to the individual. I can't help but note, however, that these same doctors have never been required to disclose any financial conflicts of interest they might have in determining what course of treatment to recommend. We're all supposed to take it on faith that no doctor will be influenced by the financial terms of his or her health plan contracts in the information and advice they give. Physicians also decide if the individual's judgment is impaired, if the desire to die seems rational to them.

The Oregon law immunizes physicians from being accountable for each of these decisions.

The reasons doctors actually report for issuing lethal prescriptions are the patient's "loss of autonomy" (86%), "less able to engage in activities" (85%), "loss of dignity" (83%), and "feelings of being a burden" (37%).<sup>9</sup> People with disabilities are concerned that these psycho-social factors are being widely accepted as sufficient justification for assisted suicide, with most physicians not even asking for a psychological consultation (14%)<sup>10</sup> or the intervention of a social worker familiar with home and community based services that might alleviate these feelings. The societal message is "so what?" or "who cares?"

The primary underlying practical basis for the physician's determination that the individual is eligible for assisted suicide is the individual's disabilities and physical dependence on others for everyday needs, which is viewed as depriving them of what non-disabled people often associate with "autonomy" and "dignity," and may also lead them to feel like a "burden." This establishes grounds for physicians to treat these individuals completely differently than a physically able-bodied suicidal person would be treated.

In effect, the Oregon Law gives physicians the power to judge whether a particular suicide is "rational" or not based on his or her evaluation, or devaluation, of the individual's quality of life, and then to actively assist certain suicides based on that

judgment. The Oregon Death With Dignity Act authorizes and empowers physicians to discriminate in their response to a patient's expression of the wish to die based on the patient's disability. This should be viewed as a violation of the Americans with Disabilities Act, which prohibits such discrimination.

#### The Impact of Assisted Suicide Laws on Others

But perhaps the most important question is not whether the rights of the few people who request assisted suicide and get it have been compromised, though that is a concern, but whether legalizing these individual assisted suicides has a broader social impact. Does it matter that a society accepts the disability-related reasons that people give for assisted suicide, declares the suicide rational and provides the lethal means to complete it neatly? Does it harm people who are not deemed eligible for assisted suicide under the current version of the law, but nevertheless experience severe illnesses and newly acquired disabilities as a loss of dignity and autonomy?

To assess that, I think we should look at the fact that Oregon has the fourth highest elder suicide rate in the country. From the disability rights perspective, this is not surprising. In the face of constant social messages over nearly two decades that needing help in everyday living robs one of dignity and autonomy, makes one a burden and justifies state sponsored suicide, maybe Oregon's elders have taken this disgusting and prejudicial message to heart.

What looks to some like a choice to die begins to look more like a duty to die to many disability activists. I have yet to see an article in which the Oregon health authorities who profess concern about the high rates elder suicide rates go so far as to even mention the Oregon Death With Dignity Act, much less examine the social message behind it. From a disability rights perspective, the potential connection seems obvious.

#### The Erosion of Protections for People in Guardianship

Assisted suicide laws and practices do not stand in isolation, but arise in the context of a larger health care system that also includes substitute decision-making affecting the lives of people who are deemed "incompetent" or not capable of making and communicating their own decisions. Determinations of "incompetence" are made both formally through the courts, and informally, depending on state laws and health care provider policies. A competent individual may direct their future medical care during a potential period of incompetence through the use of an advance directive. An advance directive can specify the medical treatments that an individual would accept or refuse in various circumstances.<sup>11</sup> In addition or in the alternative, an advance directive can designate a substitute or proxy whom the individual trusts to weigh the complex information and factors that may be involved in a specific health care decision.

Health care decisions for people deemed incompetent are generally governed by state laws. Substitute decision-makers may be proxies chosen by the individual while competent, or surrogates appointed according to a priority list established in state law (the

list usually beginning with the spouse and ending with the public guardian). Surrogate decisions are supposed to be based on what the individual's wishes would have been, if competent.

However, most states have laws permitting health care providers to avoid compliance with advance directives. When the provider refuses to withhold or withdraw treatment the patient doesn't want (a rarity these days), these provisions are referred to as "conscience clauses" and usually require some effort to transfer the patient to another provider. When the provider refuses to provide desired care (common these days), these provisions are called "futile care" policies.

Several court cases have arisen from family disputes involving people who became incompetent without executing an advance directive. Before the well-known case of Terri Schiavo in Florida, there was the case of Robert Wendland in California. Both Mr. Wendland's wife and mother agreed that he was not in a "persistent vegetative state," and that he had not left clear and convincing evidence of his wishes. Nevertheless, his wife argued that she should be able to remove his tube feeding anyway. A state statute, based on a national model health care decisions code, gave her the right to starve and dehydrate him even if he had expressly requested food, and forty-three bioethicists filed a friend of the court brief in agreement, under the authorship of Jon Eisenberg.

Ten disability rights organizations filed in support of the mother's view, and against the general presumption that no one would want to live with his disabilities, which was being used to justify lowering constitutional protections of his life. Ultimately, the California Supreme Court agreed that Mr. Wendland's life could not be taken without clear and convincing evidence of his wishes.<sup>12</sup> Unfortunately, this ruling was issued three weeks after he died from pneumonia, having been deprived of antibiotics.

By the time the Schiavo case reached major national attention in 2003, twenty-six national disability organizations had taken a position that Terri Schiavo should receive food and water, due to the highly conflicting evidence of her wishes and the fact that she had not chosen her own guardian. We were deeply disturbed to see court after court uphold questionable lower court rulings. This time, Jon Eisenberg and 55 bioethicists supported the removal of food and water. Disability rights groups were also disturbed that the court allowed most of Terri Schiavo's rehabilitation funds to be spent on her husband's lawyers, that she was denied a properly fitted wheelchair, a swallowing test and therapy, the potential for oral feeding, speech therapy, and the freedom to leave the hospice with her parents, even temporarily. Despite media reports to the contrary, the autopsy report was not inconsistent with a finding that she was in a minimally conscious state and could have benefited from these things. And we were concerned that adult protective services did not intervene, and the state protection and advocacy agency tried but proved powerless.

It would appear that the prevalent prejudice that no one would want to live like Terri Schiavo translated into her guardian's unfettered right to treat her at best as a prisoner, at worst as though she was already dead. Too many of us have been told by someone that

he or she could not stand to live the way we are. Too many of us have been forced into institutions and locked away.

Nevertheless, the perspectives of such prominent national groups as The Arc of the United States (formerly the Association for Retarded Citizens), the National Spinal Cord Injury Association, the National Council on Independent Living, and many others were consistently ignored by most of the press, as well as the courts.

Unfortunately, the anecdotal evidence suggests that Terri Schiavo's case may be the tip of a very large and almost fully submerged iceberg. I've been a health care advocate for a couple decades, often joining street protests against government health cuts. One mission of the end-of-life care movement is a good one, to educate health care providers about how to provide good palliative care, but another mission is to shape public policy on health care. It appears that a certain line of thought in bioethics has pretty much taken over the policy-making work. This line of thought involves a lifeboat approach, deciding who gets thrown out.

This week, I received a phone call from a woman with three children and an ex-husband who died Sunday. She had found Not Dead Yet on the internet. Her ex-husband, age 35, had been in a car wreck on April 2<sup>nd</sup>. She said that he had been on a ventilator until two weeks ago, but had been weaned from it. She described ways in which he seemed to be slowly improving in responsiveness. But from the beginning, the doctors in Peoria, Illinois, had urged the man's mother and all of his family to withhold treatment. Last Thursday, they finally persuaded his mother to remove his food and fluids. Had he survived until Monday, a lawyer was set to go into court and argue that the mother should not have been guardian due to alcoholism and other factors that made her susceptible to pressure, but too late. I'm getting too many calls like this from people being pressured.

For the last three decades, mainstream bioethicists have told the press and the public that euthanasia is about "compassionate progressives" versus the "religious right" and have equated their proposals with "patient autonomy" and the "right to die". Nevertheless, these bioethicists are actually talking about the legal parameters for statutory guardians and health care providers to medically end the lives of people with disabilities, especially cognitive disabilities, on a discriminatory, non-voluntary and involuntary basis. Based on their well-funded policy work, it often takes more documentation to dispose of our property than to dispose of our lives. This affects people with brain damage resulting from birth injuries, accident or trauma, strokes and dementia, and other causes.

One of the leaders of the end-of-life care movement, Dr. Ira Byock, was interviewed by Ragged Edge Magazine, a leading disability rights publication. He stated that Partnership for Caring and Last Acts, national leaders in the movement until they disappeared under a cloud late in 2004, had excluded the disability perspective, and that this exclusion was "deliberate and irresponsible." What's especially disturbing is that they had fifteen years and hundreds of millions in funding from prominent foundations, and set up surrogate decision-making protocols to end the lives of people with intellectual disabilities, without seeking the input of such individuals and the established organizations that address issues

of self-determination for people who have less typical ways of receiving, processing and communicating information.

What might other disability groups have brought to the discussion table?

There are many journal articles about the problems with advanced directives. A consistent finding in several funded studies is that people change their minds about what treatments they want, and what level of disability they will accept, as they move through the experience of having increasing disabilities. The disability community has a response to that, to use a popular phrase, "well, duh."

And you may have seen reports of an Alzheimer's study in 2004. It confirmed previous studies that caregivers have a lower opinion of their relative's quality of life with Alzheimer's than the persons themselves have, and found an explanation for the discrepancy. The caregivers project their own feelings about the burden of care-giving onto the person they care for.<sup>13</sup> Once again, the disability community response is "well, duh." And these are the very caregivers who make life-ending decisions.

Policies on removal of food and water have serious and far-reaching implications. Many people in nursing homes are on feeding tubes not because they cannot eat orally, but because there are not enough staff to help them eat.<sup>14</sup> One study also found that in for-profit nursing homes, African-Americans with dementia are taken off hand feeding and put on a feeding tube sooner in the disease process than their white counterparts.<sup>15</sup> Abracadabra, the individual is then on "life support," the kind that can be removed by a third party decision-maker.

Another key issue for protection of people in guardianship is the problem of state guardians, who may have an inherent conflict of interest due to the state's role in Medicaid. The Kentucky Supreme Court ruled in 2004 that a public guardian may deprive life sustaining treatment from a man labeled mentally retarded, despite the financial conflict of interest for a state guardian of a ward on Medicaid.<sup>16</sup> Another state guardian case involved Haleigh Poutre, an 11-year-old girl in Massachusetts who was allegedly beaten into a coma by her stepfather and whom the state wanted to remove from life support earlier this year. The resulting legal dispute bought a little time. The court agreed to remove life support, but by then Ms. Poutre defied physician pronouncements, woke up and was transferred to rehabilitation.<sup>17</sup>

### **Futility**

Now, increasingly, another type of third party medical decision threatens older and disabled people, decisions by physicians in open opposition to the patient, their surrogate or their advance directive, i.e. futility. A big part of many futile care policies is an Ethics Committee that holds meetings to persuade the family that they should agree with the doctor and thereby avoid the potential for litigation. This was the strategy suggested in a 1999 article in the Journal of the American Medical Association.<sup>18</sup> But if the doctor can't convince the surrogate to withhold treatment, then they may overrule the surrogate.

Futile care policies provide that a doctor may overrule a patient or their authorized decision-maker in denying wanted life-sustaining treatment. Futile care policies do not generally require that the treatment be objectively futile, but allow doctors to use subjective criteria such as quality of life judgments as grounds for denying treatment.

Studies consistently demonstrate that physicians and other health care providers rate the quality of life of people with significant disabilities and illnesses significantly below the individual's rating of their own quality of life.<sup>19</sup> These health care providers may also be financially penalized for providing too much health care (contracts call it "over-utilization"). We've learned that lawyers rarely take wrongful death cases involving people with significant illnesses, because damages are generally calculated based on lost earnings, and cause of death may be hard to prove. So there's very little protection for consumers with expensive needs.

Recently, a Texas futility case received some media attention.

Andrea Clark, a conscious heart surgery patient in Houston was sentenced to die before her time in Texas under its "Futile Care" statute. An "ethics committee" told her family that life support would be removed ten days after they were given notice. The Texas law allows the ethics committee to give only 48 hours notice for a meeting, but HIPAA allows providers 72 hours before medical records must be provided to the family. Both before her surgery and when not drugged into unconsciousness afterward, Ms. Clark herself made her wishes in favor of treatment very clear. She had reportedly been declared terminal five years earlier and repeatedly survived her predicted demise. Through massive efforts, including protests and legal wrangling, the hospital relented and Ms. Clark spent an extra week with her family, including her 23-year-old son, before she died. But why did her family have to fight for her wishes to be honored?

Disability rights leader Bob Kafka said of the Texas law, "The essence of the futility law embraces involuntary euthanasia. The ability of a doctor to overrule both the patient and their surrogate in withdrawing life-sustaining treatment is a violation of the principle of patient autonomy. This law can't be fixed, it needs to be killed -- or euthanized."

### **Active Euthanasia**

My colleague Dr. Carol Gill, a disabled psychologist, delivered a keynote address at a 2001 conference, sponsored by Neiswanger Institute for Bioethics and Health Policy, at Loyola University of Chicago.<sup>20</sup> She detailed the events leading up to the death of her mother-in-law, who had become increasingly disabled over a seven year period, and lived in an assisted living facility. A daughter was the woman's guardian. The mother was hospitalized after a stroke. Though she had not had a swallowing test, the mother was on a feeding tube. At one point, the guardian/daughter and doctor withheld feeding for four days without the agreement of the rest of the family, but mother kept asking for ice cream, so they relented. But by then she was weakened, and soon seemed to be nearing the end of her life. One morning, the daughter asked the doctor to get it over with, so her



morphine dose was increased until she died. I thought about Dr. Gill's story when I heard the news about a new law in Colorado.

On April 4<sup>th</sup>, the Governor signed a bill pushed by the pro-assisted suicide advocacy group, Compassion and Choices. Senate Bill 102 protects doctors and caregivers from being prosecuted under the manslaughter statute for giving palliative care to the terminally ill. According to one of the bill's proponents, "No Colorado physician delivering palliative-care medications has been charged with manslaughter, but many physicians have hesitated to prescribe painkillers to terminally ill patients out of fear of prosecution." Now, I always thought they were afraid of prosecution under drug laws, not manslaughter statutes.

Why didn't they seek immunity from drug laws? What is the motivation for manslaughter immunity? What group besides doctors could be powerful enough to get a statute to protect them from a non-existent problem of prosecution just because they wrongfully deny patients pain relief? How is that that the medical profession is afforded such lack of accountability?

Years ago, Kathryn Tucker of Compassion and Choices wrote about a case involving non-voluntary withholding of food and water, and concluded that "a wide chasm exists between the requirements of Washington state law and medical practice"<sup>21</sup> when it comes to health care decisions. There are two ways to respond to that problem. One is to enhance consumer protection by increasing the accountability of health care providers. The other is to rewrite the laws to correspond to actual practice. This is already being done for surrogacy laws and futility laws. Is the Colorado statute another example of the same phenomenon, ensuring that doctors won't risk prosecution for active euthanasia of people who have agreed to palliative care?

#### **Back Door Euthanasia – Rationing and Budget Cuts**

Back before the patient autonomy movement of the 1970's and 1980's, doctors did make all the life and death decisions. Now, some doctors think that patients and their families have gone too far in demanding medical treatment for people who are too old and have advanced chronic health impairments. Some physicians and lawyers think that health care resources need to be rationed, and that physicians know best who should receive health care.

These lifeboat bioethicists seem to think of themselves as progressives, but oddly they never spend much energy on ways to cut unnecessary costs before cutting lives. My sister recently started a new career as a medical assistant at a practice with 25 doctors in Michigan. She said that four days out of five, she doesn't have to buy lunch because it's catered in by pharmaceutical companies. Marketing costs. But rather than spending all that professional brain power on conquering the waste and inhumanity of a profit-driven health care system, these bioethicists are pushing new health care decisions laws to kill disabled people who aren't going to die soon enough for their taste without a little push.

In the face of these developments, the disability rights movement has expertise to bring. But we also have an attitude about disability that diverges from the mainstream, especially the mainstream of bioethics. Frankly, I think that's why we were deliberately excluded from the last decade of policy making conducted off the public radar screen, why the right-wing-left-wing script was so important to these bioethicists, no matter how untrue and exclusionary.

Basically, the bioethicists have warped the palliative care movement into a life-ending movement. They've had hundreds of millions of dollars to work with, and they've used it to build a steamroller that's decimating the civil and constitutional rights of people whose lives are viewed as too marginal to merit support. This affects more than the disability community of today, it affects everyone, directly or through family, sooner or later. A privileged few are making the rules for who lives and who dies, but it's happening behind closed doors and has not been subject to public discussion. The Texas chapter of Not Dead Yet just resigned from a Texas Advance Directives Coalition, calling for just such a public discussion. But this is relevant in all states and at the federal level as well.

If the bioethics debate can't hold up to open public scrutiny, then how can it legitimately determine what our nation's health care policies will be?

While disagreeing with mainstream bioethics, the conservatives have their own way of rationing health care. Instead of basing it on the person's health status, they base it on their economic status. For those who depend on publicly funded health care, especially in this aging society, federal and state budget cuts pose a very large threat.

I can't help but note that much of the power of the end-of-life movement has come from the fact that Medicare did not cover prescription drugs, including pain relievers. It was pure extortion to require people to agree to forego curative treatment in order to get pain relief, and I've been terribly disturbed to see that the new Medicare prescription drug coverage does not include the primary pain relieving medications, continuing the pattern of extortion that forces people to agree to hospice, refuse curative treatment, and accept a potentially premature death in order to receive pain relief.

#### **How Can Federal Legislators Help?**

##### **OPEN PUBLIC DISCUSSION**

Foster open public discussion of these policies. At this point, people find out about futility when a family member is denied treatment they want. We think that futility policies are unconstitutional, but the wider public needs to know before policy actions can be formulated. And disability rights groups must be included.

##### **MEANINGFUL FEDERAL REVIEW**

Under Medicare and Medicaid law, you could provide for meaningful federal review of contested third party decisions to withhold treatment in the absence of an advance directive or personally appointed surrogate. Uphold a clear and convincing evidence standard with teeth in it. Uphold a presumption for food and fluids.

**CONGRESSIONAL STUDY**

Ever since the *Cruzan* decision in 1990, people with disabilities, old and young, have been starved and dehydrated based on surrogate or health provider decisions, but we don't know who, why, how or what factors were involved. We also know that physicians are overruling patient autonomy and denying treatment under futility policies. You could ask for all hospitals to send you their futility policies. Congressional examination of the impact of existing policies is necessary.

**STATE-BY-STATE REVIEW OF LAWS AND POLICIES**

Funding for a disability-rights-based state-by-state review of guardianship and health care decisions laws is needed, along with comprehensive efforts to develop reforms to safeguard against non-voluntary and involuntary euthanasia.

**PUBLIC EDUCATION BY PEOPLE WITH DISABILITIES**

There should be funding for public education about the perspectives of people living with significant disabilities on the difference between end-of-life decisions and decisions to end the lives of disabled people who are not otherwise dying.

**OLMSTEAD IMPLEMENTATION, PASSAGE OF MICASSA**

The civil rights of people with disabilities to long-term supports in the community under the U.S. Supreme Court decision in *Olmstead* should be implemented. We call for passage of the Medicaid Community Attendant Services and Supports Act, which would allow people receiving Medicaid funding to have a life in the community instead of being forced into a nursing home. This bill also includes consumer-directed options that maximize personal responsibility and reduce costs.

**SUSTAIN GOVERNMENT FUNDED HEALTH CARE PROGRAMS**

Conservatives who honestly supported efforts to protect the life of Terri Schiavo should work on a bipartisan basis with moderates and liberals to ensure continued appropriate funding of Medicare and Medicaid.

**Conclusion**

To conclude, regardless of our abilities or disabilities, none of us should feel that we have to die to have dignity, that we have to die to be relieved of pain, or that we should die to stop burdening our families or society. Cognitive abilities must not be allowed to determine personhood under the laws of the United States. Reject the script you have been given by the right to die and the right to life movements. Instead, listen to the disability rights movement. We are your advance guard, in anticipation of the aging of our society, with decades of experience in living with disability and on the front lines of the health care system. We offer a very different vision, as well as the practical know-how and leadership to help build a society that respects and welcomes everyone.

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**Senate Judiciary Committee  
Subcommittee on the Constitution, Civil Rights, and Property Rights**

**Hearing on "The Consequences of Legalized Assisted Suicide and Euthanasia"**

**Statement of Senator Russ Feingold**

Thank you Mr. Chairman. I want to join you in welcoming our witnesses, and I thank you and your staff for working with us to put together balanced panels on this difficult and emotional topic. I sincerely admire all of our witnesses' dedication and commitment to the quality of care for the terminally ill.

Patients who suffer from terminal illnesses face, along with their families, decisions that most of us would rather not make. End-of-life decisions, such as the refusal or withdrawal of life-sustaining medical treatment and whether to seek palliative care that may hasten a patient's death, raise very difficult questions of how to reconcile patient autonomy, advances in medical technology, and religious precepts. Whether terminally ill patients should have some say in the manner and time of their deaths is a complicated and extraordinarily wrenching public policy issue. These are consequential decisions that Americans face every day. No one, least of all the government, can answer those questions for every patient or every family in every situation. To the greatest extent possible, recognizing, of course, the need to protect vulnerable elderly or disabled individuals from pressure and abuse, government should leave these decisions to patients and their families in consultation with their medical and spiritual advisors.

Under what circumstances a terminally ill or comatose patient has the right to die according to his or her wishes -- the so-called "right to die" debate -- requires careful consideration of numerous complicated medical, ethical, and legal factors. Congress should not repeat the mistake it made last year when it tried to interfere with a state court's proceedings concerning Terri Schiavo. I hope that today's hearing will shed light on these issues and allow us to act more carefully and with more humility in the future.

The Supreme Court held in the 1997 decision *Washington v. Glucksberg* that there is no constitutional right to assisted suicide. The opinion noted, however, that state legislatures had begun to evaluate physician assisted suicide. And Justice O'Connor noted in her concurrence in the case: "There is no reason to think the democratic process will not strike the proper balance between the interests of terminally ill, mentally competent individuals who would seek to end their suffering and the State's interests in protecting those who might seek to end life mistakenly or under pressure."

In 1994, the voters of the state of Oregon approved the Oregon Death with Dignity Act, which allows for state-licensed physicians to dispense or prescribe a lethal dose of drugs upon the request of a terminally ill patient. That law, the first of its kind in the country,

survived efforts to repeal it in the state legislature and was passed in a second statewide referendum in 1997. The law was upheld against a constitutional challenge. Then the Department of Justice tried to prevent it from being implemented, but a 6-3 majority of the Supreme Court in *Gonzales v. Oregon* ruled that the Attorney General could not use the Controlled Substance Act to prohibit doctors from prescribing regulated drugs for use in physician assisted suicide under Oregon law.

I am pleased that Senator Wyden has joined us today to give his perspective on his state's experience. In addition, two of our witnesses today, Ann Jackson and Julie McMurchie, are from Oregon and have firsthand knowledge of how the Death with Dignity Act has worked.

I look forward to hearing the insights offered by our witnesses today. Thank you.

**Testimony of Jonathan Imbody**  
Christian Medical Association  
U.S. Senate Committee on the Judiciary  
Subcommittee on the Constitution, Civil Rights and Property Rights

May 25, 2006

Senators, thank you for the privilege of testifying today.

I serve as Senior Policy Analyst with the Christian Medical Association, a professional organization of 17,000 members.

I spent several months in the Netherlands a few years ago researching personal accounts of euthanasia.

I knew from published medical studies that Dutch doctors admitted, on condition of anonymity, to putting approximately 1,000 patients to death a year *without* the patients' request.<sup>i</sup>

I interviewed Dr. Zbigniew Zylich, a Polish-born internal medicine and oncology specialist who has practiced in the Netherlands since 1979.

Dr. Zylich told me about his experience with an elderly patient in an academic hospital:

He said, "[My patient] was afraid to go to the hospital because she was afraid of euthanasia. She was not asking for this; she did not even want this. And they promised her that nothing would happen to her.

"I admitted her on the weekend to a bed of another patient who would be coming back Monday morning. I had no other facility for her. She was very ill, and I expected she would die on the weekend.

"But she improved. With good treatment and pain control, she started to talk and she was not dead."

"On Monday morning when I went off from my shift and went home, my colleague came and did something. I don't know exactly what he did, but she died within ten minutes. And the nurses called me at home. They were very upset about this. And I was very upset about this, too.

Dr. Zylich added, "And this was not the only single case. This was the *whole system* working like this."

The Dutch have a lot of faith in their dikes and in their regulations. But euthanasia introduces dangerous gray areas of decision making by doctors and by vulnerable patients who feel pressured to die. These gray areas defy regulation.

I interviewed a Dutch couple, Ed and Xandra, who told me about Ed's father, Franz.

Franz was a Dutch sailor who had reluctantly entered the hospital for pain relief. Doctors discovered that Franz had a terminal illness.

Franz's son Ed recalls, "We were all invited to the hospital when [the doctors] said the diagnosis. The doctors told my Dad, 'Well, you don't have too long to live. We can't guarantee anything, but if we operate, you could live longer and have more time to be with your kids.'"

Ed recalls, "When the doctors left, my sister said it very bluntly, just putting it on the table: 'What about euthanasia?' she said."

Franz's wife did not protest. Xandra suggests that's because Franz's wife was angry with him and thought Franz had been unfaithful in their marriage.

So Franz agreed to euthanasia.

Xandra remembers the day the doctor came to put her father-in-law to death.

"[The doctor] had all those little vials," Xandra recalls, "and she had two injections—one to put him to sleep, and one for the killing part.

"She was very, 'OK, I need to do this now.' Probably she had another appointment after that.

"Then she started injecting him," Xandra recalls.

"While she was giving the injection, I was standing at [my father-in-law's] feet. He was really looking at me and at our baby—I was holding the baby at the time."

Then, Xandra says, her father-in-law suddenly cried out.

He said, "I don't want to die!"

Xandra frantically looked to the doctor and at the others in the room.

"But no one was reacting," she recalls.

She didn't know what to do.

"And then," she says, "he was ... like he was in a deep sleep. So then the doctor started getting the other injection. Then I left the room."

Franz died from that second injection, whether he really wanted to or not.

Once a country casts off millennia of Hippocratic and Judeo-Christian prohibitions against suicide and euthanasia, the ship drifts farther and farther out to sea with no anchor.



If we assume the power to kill patients who ask for it, why not kill disabled patients who cannot ask for it? If we assume the power to kill patients with physical illnesses, why not kill patients with emotional illnesses? If we assume the power to kill the elderly who have medical problems, why not kill infants who have medical problems?

This slippery slope is not theoretical; this is exactly what has happened in the Netherlands.<sup>ii,iii,iv</sup>

And it can happen anywhere, unless we provide truly compassionate alternatives to state-sponsored suicide:

- More doctors need advanced training in palliative care.
- In certain cases, more aggressive pain-relief prescribing regulations will help doctors provide more effective relief for patients.
- Hospice care can provide tremendous benefits for patients and families.

Perhaps the most important help for terminally ill patients transcends medicine. The unconditional, persevering love of family, friends and God can provide us with incomparable strength, courage and hope beyond our physical condition.

Thank you.

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"Controversial cases have tested the boundaries of euthanasia's application, none more so than that of a 25-year-old woman who had suffered anorexia for 15 years and who had been in hospital and through therapy without success. She repeatedly begged her doctor to help her die and threatened violent suicide if he would not. She went so far as to videotape her plea for euthanasia and the doctor agreed."

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**Testimony of Ann Jackson  
Executive Director/CEO  
Oregon Hospice Association**

**Before the Senate Committee on Judiciary  
Subcommittee on the Constitution, Civil Rights, and Property Rights**

**“The Consequences of Legalized Assisted Suicide and Euthanasia”  
Thursday, May 25, 2006**

Oregon's Death With Dignity Act (ODDA) allows a terminally-ill resident of the state to ask his or her doctor for a prescription of life-ending medication. “Physician-assisted suicide” is a term often used to describe the provisions of the ODDA, although actions taken within the law do not “constitute suicide, assisted suicide, mercy killing, or homicide.”<sup>1</sup> The law does not allow euthanasia.

A citizen's initiative, the ODDA passed by a margin of 51% to 49% in 1994. A repeal effort in 1997 was defeated 60% to 40%. The Act was effectively implemented in 1998, when the first of many federal challenges was resolved. In January, 2006, the US Supreme Court ended the most recent when it ruled that states, and not the Justice Department, have the authority to regulate medical treatment for the terminally ill.

The Oregon Hospice Association (OHA) was relieved by the Supreme Court's decision. Not because we support—or oppose—Oregon's Death With Dignity Act, but because the repercussions of a decision in favor of the Justice Department would have added to the chilling impact regulatory scrutiny has on pain management.<sup>2 3 4</sup>

And because a decision against Oregon would have curtailed the contributions Oregon's health care community is making in our “laboratory of the states”.

In its first eight years, the ODDA has been responsibly implemented with none of the predicted dire consequences. Reports issued by the State of Oregon, as required by the Act, and peer-reviewed and published research studies, confirming and adding to state data, are closing the void that existed because assisted dying had never before been practiced in a legal environment. We are learning from that body of knowledge, applying it to improve end of life care in Oregon. It is knowledge that has application well beyond our borders.

Physician-assisted dying is not disproportionately selected, as was predicted, by those who lack financial resources, health insurance, family support, or an education. These individuals tend to be more highly educated, have as much or more social support, and adequate financial resources. Only two have not had health insurance. While fearing pain is a concern of those who ask for a prescription, experiencing pain is not an important factor. Physician-assisted dying is not used by people without access to hospice and palliative care: every Oregonian has access, even in the most remote and

rural areas of the state. Oregon's hospices strongly support a dying Oregonian's right to choose from among all end-of-life options.

Hospice nurses, social workers, and chaplains rank depression and financial concerns among the least important reasons an individual will ask for or use a prescription. A mental health consultation is required if an individual's judgment may be impaired by depression or another psychiatric disorder. Mental health referrals have declined over the past eight years, as physicians routinely refer patients to hospice where psychosocial and mental status is constantly assessed, addressed, and monitored.

Hospice workers have noted that violent suicide among hospice patients—always rare—is almost nonexistent, since the Act was implemented.

Health insurance or other resources for hospice care is not an issue. While care is provided without regard to a patient's ability to pay, Oregon's hospices can identify on admission individuals as immediately eligible for the Oregon Health Plan.

Although those individuals who asked for a prescription were concerned about being a burden to their caregivers, hospice workers ranked their caregivers as less likely to consider them a burden than caregivers of hospice patients who had not asked for a prescription.

Hospice workers' perspective is important because they visit patients and family caregivers often in the last weeks of life and can compare hospice patients who ask for a prescription with those who do not.

A palliative care consultation is not a requirement of Oregon's law, but almost all who have used physician-assisted dying have been offered hospice, and 88% were enrolled.

Patients' physicians identify autonomy, the ability to enjoy life, and loss of dignity as primary concerns of those who use physician-assisted dying in Oregon.

Hospice workers identify controlling circumstances of death, loss of dignity, and the desire to die at home as the most important reasons. Oregon's hospital death rate is the lowest in the nation and its home death rate, with Utah, the highest. 80% of Oregonians have an advance directive at the time of death, and respect for end-of-life wishes is virtually 100% when a POLST (physician orders for life-sustaining treatment) is in place.<sup>5</sup> The POLST, developed in Oregon, is being adopted by states throughout the country.<sup>6</sup> Hospice utilization is—and has been since the first hospices were developed in the US in the mid-1970s—among the highest in the country.

In fact, Oregon was declared a national leader in end-of-life care in 1998, before the Death With Dignity Act was implemented, and maintains its position as a leader today. It is not true that the quality of hospice and palliative care in Oregon has suffered.<sup>7 8 9 10</sup>

Only 246 individuals—not thousands, as was predicted—have ended their lives under provisions of the ODDA. Research supports our observation that many more Oregonians take comfort in the law. A study published in 2004 revealed that 1 of 200 individuals who consider assisted suicide and 1 of 25 who make a formal request will use a prescription.<sup>11</sup> Oregon's hospices describe as typical an individual who asks for a prescription on day 1, becomes qualified on day 15, and, because he or she has a plan to alleviate his or her worst fears, is able to get on with life. That the Oregon law is available, regardless of whether it is used, offers comfort.

It no longer matters whether assisted dying is right or wrong because it is a legal option in Oregon. No dying Oregonian must choose between hospice and physician-assisted dying. Oregon hospices encourage a referral to hospice of anyone who considers a request, if they aren't already enrolled. 240,000 Oregonians died in the first eight years. 246 individuals used a prescription to end their lives. One explanation for the very low rate may be the high quality of hospice and palliative care provided in Oregon.

Oregon's hospices recognized early in the public debate that hospice support, or the lack of it, would be a determining factor in whether a patient would, in fact, choose to hasten his or her death. Hospice addresses well the fears most often identified by the public as reasons for supporting the legalization of physician-assisted dying.

But autonomy and control—*not* uncontrolled symptoms—are the reasons people use a prescription.<sup>12 13 14 15</sup> One question hospice and palliative care communities and all health care providers must address is how well they respond to the needs of individuals who value most autonomy and control—and how seriously they are willing to consider such needs.

Ironically, it is those individuals who personally direct their care that get the care they need—and get it in a timely manner. Oregon's hospices agree that it's much easier to have open and honest conversations about end-of-life care when all end-of-life options are on the table.

The Oregon Hospice Association would like to think that Congress will consider carefully the potential repercussions on pain management and end-of-life care of any action it might take against Oregon. Even a proposed law can have an immediate effect of undermining physician willingness to prescribe controlled substances, as we saw in its previous attempts to compromise Oregon's law.

The Oregon Hospice Association would prefer to think that Congress will recognize—and respect the Supreme Court's belief in—the value offered in the “laboratory of the states”.

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<sup>1</sup> ORS 127.880

<sup>2</sup> <http://www.medsch.wisc.edu/painpolicy/biblio.htm>

<sup>3</sup> <http://www.painfoundation.org>

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- <sup>4</sup> <http://www.ampainsoc.org>
- <sup>5</sup> Erik K. Fromme, et al., "Increased Family Reports of Pain or Distress in Dying Oregonians: 1996 to 2002, *Journal of Palliative Medicine*, 2004-JUN-01, Vol 7, #3, Pages 431 to 442.
- <sup>6</sup> <http://www.POLST.org>
- <sup>7</sup> Hoover E, Oregon leader in nation's end of life care, *The Oregonian*, April 1998.
- <sup>8</sup> Using Qualitative and Quantitative Data to Shape Policy Change. Issue 1, June 1998. Focus: Oregon. The Robert Wood Johnson Foundation, State Initiatives (Oregon ranks first)
- <sup>9</sup> Means To a Better End: A Report on Dying in America Today. The Robert Wood Johnson Foundation, Last Acts, November 18, 2002. (Oregon ranks second)
- <sup>10</sup> Herper M, Lagorce A. The best places to die. *Forbes.com*, 2004. (Oregon ranks second)
- <sup>11</sup> Tolle S, Tilden V, Drach L, Fromme E, Perrin N, Hedberg K. Characteristics and Proportion of dying Oregonians Who Personally Consider Physician-Assisted Suicide. *J Clin Ethics*, Vol. 15, No. 2, Summer 2004
- <sup>12</sup> Ganzini, L., Harvath, T., Jackson, A., Goy, E., Miller, L., Delorit, M. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. *NEJM*, Vol. 347, No.8, August 22, 2002
- <sup>13</sup> <http://egov.oregon.gov/DHS/ph/pas/docs/year7.pdf>
- <sup>14</sup> <http://www.ohsu.edu/ethics/guidebook/toc.pdf>
- <sup>15</sup> Simopoulos N, Carlson B, Jackson A, Goy E, Ganzini L. Oregon Hospice Chaplains' Experiences with Patients Requesting Physician-Assisted Suicide, *Pall Med* 2005

**SUICIDE AND PUBLIC POLICY**

Testimony to the  
Subcommittee on the Constitution, Civil Rights and Property Rights  
Committee on the Judiciary  
United States Senate

May 25, 2006

Rita L. Marker, J.D.  
Executive Director  
International Task Force on Euthanasia and Assisted Suicide

Chairman Brownback, Senator Feingold, and Honorable Members of the Subcommittee, thank you for inviting me to testify before you today on this most urgent topic. This is an important moment historically in the debate about suicide and assisted suicide.

In 1994, Oregon transformed the crime of assisted suicide into a medical treatment when it passed the Oregon Death with Dignity Act (ODWDA). Since it went into effect in 1997, that law and experience related to it have been widely misunderstood.

**Gonzales v. Oregon and the "Ashcroft Directive": Myths and Reality**

On November 6, 2001, Attorney General John Ashcroft issued an interpretative ruling known as the "Ashcroft Directive" (Directive), stating that doctors could lose their federal registrations to prescribe federally controlled substances if they used those registrations to prescribe substances for the purpose of suicide.<sup>1</sup> He did so by finding that assisting suicide was not in the public interest and that prescribing for the *purpose* of suicide did not constitute a legitimate medical purpose under the Controlled Substances Act (CSA). The Directive was challenged immediately.

Contrary to widespread misunderstanding, the Directive, if upheld, would *not* have overturned the *practice* of assisted suicide in Oregon. Assisted suicide would have remained legal. Oregon physicians could still have assisted suicides by prescribing substances that are not controlled under federal law.

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<sup>1</sup> 66 Fed. Reg. 56,607 (2001)

Passage of the ODWDA approved the *act* of physician-assisted suicide but does not specify the *means* by which the act is to be accomplished. The law permits physicians to "prescribe medication"<sup>2</sup> for suicide but does not define "medication." Nothing in the law limits "medication" to federally controlled substances, nor does the law specifically provide that federally controlled substances are to be the means for carrying out suicide under the ODWDA. It does not refer to any particular method of inducing death other than precluding the lethal injection, mercy killing and active euthanasia.<sup>3</sup>

On January 17, 2006, in its 6-3 decision in *Gonzales v. Oregon*,<sup>4</sup> the U. S. Supreme Court found that Ashcroft had exceeded his authority when he issued his Directive. The decision was not an "endorsement" of Oregon's law, as some have claimed. Instead it was a narrow ruling dealing with the attorney general's authority to determine what is meant by a "legitimate medical purpose."

The Court's majority found that, since the CSA does not explicitly prohibit prescribing for suicide and does not explicitly declare that prescribing for suicide is not a legitimate medical purpose, the attorney general lacked authority to interpret it as doing so. According to the Court, it is not up to the attorney general to determine if suicide is a risk to public health and safety or if prescribing for suicide is a legitimate medical purpose under federal law. Instead, it is up to Congress to do so "by explicit language in the statute."<sup>5</sup>

### The Experience in Oregon

In *Gonzales*, the U.S. Supreme Court summarized Oregon's assisted-suicide law:

The statute gives attending physicians a central role, requiring them to provide prognoses and prescriptions, give information about palliative alternatives and counseling, and ensure patients are competent and acting voluntarily. § 127.815. Any eligible patient must also get a second opinion from another registered physician, § 127.820, and the statutes' safeguards require physicians to keep and submit to inspection detailed records of their actions, §§ 127.855, 127.865.<sup>6</sup>

<sup>2</sup> Or. Rev. Stat. 127.800 to 127.897.

<sup>3</sup> Or. Rev. Stat. 127.880.

<sup>4</sup> *Gonzales v. Oregon*, 126 S. Ct. 904 (2006).

<sup>5</sup> *Id.* at 924.

<sup>6</sup> *Id.* at 923.

That summary, containing what are generally referred to as some of the ODWDA's "safeguards," conveys a notion of a carefully written, protective law. However, the experience in Oregon contradicts the effectiveness of safeguards, making it clear that their protective nature is a mere illusion. A telling example of this is contained in the official published transcript of closed door hearings conducted in Oregon by members of the British House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill. Committee members traveled to Oregon seeking information regarding Oregon's assisted-suicide law for use in their deliberations about a similar proposal under consideration in Parliament.<sup>7</sup>

After hearing many witnesses claim that there have been no complications associated with more than 200 assisted-suicide deaths, committee member Lord McColl of Dulwich, a surgeon, expressed skepticism. He said, "If any surgeon or physician had told me that he did 200 procedures without any complications, I knew that he possibly needed counseling and had no insight. *We come here and I am told there are no complications. There is something strange going on.*"<sup>8</sup>

Another committee member, Baroness Finlay, also a physician, found the Oregon experience a cause for concern rather than reassurance. Writing in the journal *Palliative Medicine*, she explained that she and others "anticipated that the evidence would sway them towards a legislative change, but in fact after carefully weighing the evidence heard by the Committee, their opinion is that a change in the UK's law on intentional killing would be unwise."<sup>9</sup>

The following contains statistical data from official reports and other published information that contradicts assurances that the ODWDA's safeguards and reporting system are protective. None of the statements below were made by opponents of

<sup>7</sup> The "Assisted Dying for the Terminally Ill Bill" was defeated in Parliament on May 12, 2006 by a vote of 148 to 100.

<sup>8</sup> Witnesses' testimony before the committee was published in: *House of Lord Select Committee on the Assisted Dying for the Terminally Ill Bill, [HL]*, Volume II: Evidence, Apr. 4, 2005. (Hereafter cited as HL.) Remarks by Lord McColl, HL, p. 334, Q. 956. (Emphasis added.) Available at: <http://www.publications.parliament.uk/pa/ld200405/ldasy/86/86ii.pdf>. (Last accessed Feb. 23, 2006.)

<sup>9</sup> I.G. Finlay *et al*, "The House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill: Implications for specialist palliative care," *Palliative Medicine*, Volume 19 (2005), p. 444.



Oregon's law.

The number of reported assisted-suicide deaths may be inaccurate or incomplete

The latest official annual Oregon report indicates that there have been 246 reported assisted-suicide deaths since the ODWDA act went into effect. This reflects an increase of more than 230% since the first year of legal assisted suicide in Oregon.<sup>10</sup> The numbers, however, could be far greater.

- From the time the law went into effect, Oregon officials in charge of formulating annual reports have conceded "*there's no way to know if additional deaths went unreported*" because Oregon's Department of Human Services (DHS), the agency designated by law to oversee assisted-suicide prescribing, "*has no regulatory authority or resources to ensure compliance with the law.*"<sup>11</sup>
- The DHS has to rely on the word of doctors who prescribe the lethal drugs.<sup>12</sup> Referring to physicians' reports, the state reporting division admitted: "For that matter the entire account [received from a prescribing doctor] could have been a cock-and-bull story. We assume, however, that physicians were their usual careful and accurate selves."<sup>13</sup>

The ODWDA contains no penalties for doctors who do not report prescribing lethal doses for the purpose of suicide.

Data for reports is based on self-reporting by doctors who prescribe lethal drugs

- Asked if there is any systematic way of finding out and recording complications, Dr. Katrina Hedberg, the lead author for several of Oregon's official reports, replied, "Not other than asking physicians."<sup>14</sup>
- Dr. Melvin Kohn, Oregon State Epidemiologist and Administrator of the department that oversees the annual reports about Oregon's law, explained that, in every case that they hear about, "it is the self-report, if you will, of the physician involved."<sup>15</sup>

<sup>10</sup> DHS, "Eighth Annual Report on Oregon's Death with Dignity Act," March 9, 2006. (<http://egov.oregon.gov/DHS/ph/pas/docs/year8.pdf>)

<sup>11</sup> Linda Prager, "Details emerge on Oregon's first assisted suicides," *American Medical News*, Sept. 7, 1998. (Emphasis added.)

<sup>12</sup> Joe Rojas-Burke, "Suicide critics say lack of problems in Oregon is odd," *Oregonian*, Feb. 24, 2000.

<sup>13</sup> Oregon Health Division, *CD Summary*, vol. 48, no. 6 (March 16, 1999), p. 2.

(<http://www.ohd.hr.state.or.us/chs/pas/pascdsm2.htm>)

<sup>14</sup> Hedberg, HL, p. 263, Q. 597.

<sup>15</sup> Kohn, HL, p. 263, Q. 598.

"Safeguards" are disregarded and no one has been disciplined

- Referring to assisted-suicide cases that were in violation of the law – where only one of the required two witnesses signed the request or where doctors prescribed the lethal drugs without waiting for 15 days as the law requires – Dr. Hedberg said, "[T]here have been a number [of such violations] over the years."<sup>16</sup>
- Kathleen Haley, Executive Director of the Oregon Board of Medical Examiners, said four such cases, one involving multiple patients,<sup>17</sup> were reported to the Board of Medical Examiners. This resulted in issuance of two "letters of concern" that are considered "letters of advice." She explained that the letters "are not public and they are not official disciplinary actions."<sup>18</sup>

Complications are not investigated or reported

- "[W]e are not given the resources to investigate," Dr. Hedberg said. "[N]ot only do we not have the resources to do it, but we do not have any legal authority to insert ourselves."<sup>19</sup>
- David Hopkins, Data Analyst for Oregon's Center for Health Statistics, said, "We do not report to the Board of Medical Examiners if complications occur; no, it is not required by the law and it is not part of our duty."<sup>20</sup>
- Jim Kronenberg, the Oregon Medical Associations' (OMA) Chief Operating Officer, explained that "the way the law is set up there is really no way to determine that [complications occurred] unless there is some kind of disaster." "[P]ersonally I have never had a report where there was a true disaster," he said. "Certainly that does not mean that you should infer there has not been, I just do not know."<sup>21</sup>

Psychological evaluations are rare

Under the ODWDA, depressed or mentally ill patients can receive assisted suicide if they do not have "impaired judgment."<sup>22</sup>

- The decision to refer for a psychological evaluation, Dr. Kohn said, is "up to the docs' discretion."<sup>23</sup>
- During the last three years for which reports are available, only six patients – two per year – were referred for a psychological evaluation or counseling before receiving

<sup>16</sup> Hedberg, HL, p. 257, Q. 555.

<sup>17</sup> Haley, HL, p. 323, Q. 889.

<sup>18</sup> *Id.* Q. 892.

<sup>19</sup> Hedberg, HL, p. 266, Q. 615.

<sup>20</sup> Hopkins, HL, p. 259-260, Q. 568.

<sup>21</sup> Kronenberg, HL, p. 347, Q. 1035.

<sup>22</sup> ORS 127.825 §3.03.

<sup>23</sup> Andis Robeznieks, "Assisted-suicide numbers in Oregon," *American Medical News*, Apr. 5, 2004.

prescriptions for suicide.<sup>24</sup>

- Dr. Peter Rasmussen, who has acknowledged his involvement in Oregon assisted-suicide deaths numbering into the double digits, told *American Medical News* that 75 percent of the patients who come to him are people he has never seen before and that, before writing the prescription for the lethal dose, he spends a minimum of three hours with each patient either in person *or by telephone*.<sup>25</sup>

Patient's judgment may be impaired when the prescription is filled or taken

- Although the ODWDA requires that a patient be competent when *requesting* a prescription for suicide, it does not contain any provision requiring patient competency at the time the prescription is filled or when the suicide occurs.
- Dr. Hedberg acknowledged that there is no assessment of patients after the prescription is written. "Our job is to make sure that all the steps happened *up to the point the prescription was written*," she said.<sup>26</sup> "In fact, after they write the prescription the physician may not keep track of that patient....[T]he law itself only provides for writing the prescription, *not what happens afterwards*."<sup>27</sup>

No way to track the drugs once they are received

- "[W]e do not have a way to track if there was a big bottle [of lethal drugs] sitting in somebody's medicine cabinet and they died whether or not somebody else chose to use it," explained Dr. Hedberg.<sup>28</sup>

Self-administration is very broadly interpreted

- Dr. Rasmussen explained that, in one case, he opened 90 capsules – a lethal dose – of barbiturates and poured the white powder into a bowl of chocolate pudding. He gave the mixture to the woman's son who spooned the mixture into his mother's mouth. Another son gave her sips of water to wash the solution down. The woman died twelve hours later.<sup>29</sup>
- According to Sue Davidson of the Oregon Nurses Association (ONA), a 2002 survey found that nurses were very actively involved in the process and that "some indicated that they had assisted [patients] in the taking of it [the lethal dose]."<sup>30</sup>

<sup>24</sup> DHS, "Eighth Annual Report on Oregon's Death with Dignity Act," March 9, 2006, pg. 23, Table 4.

<sup>25</sup> Andis Robeznieks, "Oregon sees fewer numbers of physician-assisted suicides," *American Medical News*, Apr. 4, 2005.

<sup>26</sup> Hedberg, HL, p. 259, Q. 566. (Emphasis added.)

<sup>27</sup> *Id.* Q. 567. (Emphasis added.)

<sup>28</sup> *Id.* p. 262, Q. 591.

<sup>29</sup> Jennifer Page, "A Death in Oregon: One Doctor's Story," *Washington Post*, Nov. 3, 1999.

<sup>30</sup> Davidson, HL, p. 352-353, Q. 1058.

Lethal drugs do not need to be taken orally

The ODWDA bars a physician from administering a lethal injection to a patient.<sup>31</sup>

However, it does not explicitly specify the route by which the lethal drugs must be taken.

- Barbara Glidewell who educates Oregon Health & Science University (OHSU) patients and their families about "the need for a dying plan and to rehearse the plan"<sup>32</sup> said that patients who cannot swallow would "need to have an NG [nasogastric] tube or G [gastrostomy] tube placement."<sup>33</sup> Then, they could "express the medication through a large bore syringe that would go into their G-tube."<sup>34</sup>
- Oregon's 2005 *Guidebook for Health Care Professionals* states, "It remains unclear whether the Oregon Death with Dignity Act allows an attending physician to prescribe an injectable drug for the patient to self-administer for the purpose of ending life."<sup>35</sup>
- Discussing a case in which a man said he helped his brother-in-law take the drugs, Dr. Hedberg said that "we do not know exactly how he helped this person swallow, whether it was putting a feed tube down or whatever, but he was not prosecuted...."<sup>36</sup>

Required life expectancy of six months or less is considered unrealistic or unimportant

- Kronenberg of the OMA said most physicians have told him that trying to predict that a patient has less than six months to live "is a stretch." "Two hours, a day, yes, but six months is difficult to do," he explained.<sup>37</sup>
- Dr. Rasmussen said life expectancy predictions for a person entering the final phase of life are inaccurate. He dismissed this as unimportant, saying, "Admittedly, we are inaccurate in prognosticating the time of death under those circumstances, *we can easily be 100 percent off*, but I do not think that is a problem. If we say a patient has six months to live and we are off by 100 percent and it is really three months or even 12 months, I do not think the patient is harmed in any way...."<sup>38</sup>

<sup>31</sup> Or. Rev. Stat. 127.880.

<sup>32</sup> Glidewell, HL, p. 268, No. 3.

<sup>33</sup> *Id.* p. 270, Q. 623.

<sup>34</sup> *Id.* p. 275, Q. 653.

<sup>35</sup> *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals* (2005), developed by The Task Force to Improve the Care of Terminally-Ill Oregonians, convened by The Center for Ethics in Health Care, Oregon Health & Science University; Chapter 10, Pharmacists and Pharmacy-Related Issues, p. 4. Available at: <http://www.ohsu.edu/ethics/guidebook/chapter10.pdf>. (Last accessed Feb. 23, 2006.) The guidebook notes, "The Act specifically states: 'Nothing in ORS 127.800 to 127.897 shall be construed to authorize a physician or any other person to end a patient's life by lethal injection....'" [Chapter 10, p. 4. (Emphasis added.)] It does not specifically state that a patient cannot end his or her own life by lethal injection.

<sup>36</sup> Hedberg, HL, p. 267, Q. 621.

<sup>37</sup> Kronenberg, p. 351, Q. 1054.

<sup>38</sup> Rasmussen, HL, p. 312, Q. 842. (Emphasis added.)

Pain control has become increasingly inadequate

- As of 2004, Oregon nurses reported that the inadequacy of meeting patients' pain needs had increased "up to 50 percent even though the emphasis on pain management has remained the same or is slightly more vigorous....Most of the small hospitals in the state do not have pain consultation teams at all," Davidson of the ONA said.<sup>39</sup>

Records used in annual reports are destroyed

- Dr. Hedberg said, "After we issue the annual report, we destroy the records."<sup>40</sup>

Doctors decide what "residency" means

- Under Oregon's law, a patient must be a resident of Oregon.<sup>41</sup> Residency can be demonstrated by means that include [but are not limited to] a driver's license or a voter registration, but, according to Dr. Hedberg, "It is up to the doctor to decide" whether the person is a resident. There is no time element during which one must have lived in Oregon. "If somebody really wanted to participate, they could move from their home state," she said. "I do not think it happens *very much*...."<sup>42</sup>

An assisted-suicide advocacy group facilitates most of Oregon's assisted suicides

- According to Dr. Elizabeth Goy of OHSU, Compassion in Dying (the assisted-suicide advocacy group that merged with the Hemlock Society and is now called Compassion and Choices<sup>43</sup>) sees "almost 90 percent of requesting Oregonians...."<sup>44</sup>
- Barbara Farmer of the Visiting Nurses Association said, if a person's own doctor doesn't want to participate, "we have advised them to work with Compassion in Dying...."<sup>45</sup>

Is it the intent of Congress that federal registrations be used to facilitate activities such as those described above? Is it the intent of Congress that federal registrations be used for the purpose of facilitating suicide in other jurisdictions if such jurisdictions pass laws similar to, or even more expansive, than Oregon's law?

<sup>39</sup> Davidson, HL, p. 357-358, Q. 1098.

<sup>40</sup> Hedberg, HL, p. 262, Q. 592.

<sup>41</sup> Or. Rev. Stat. 127.860, § 3.10.

<sup>42</sup> Hedberg, HL, p. 267, Q. 620. (Emphasis added.)

<sup>43</sup> The co-director of Compassion and Choices was the chief petitioner for the Oregon law. Currently Compassion and Choices is spearheading a California legislative measure -- the "Compassionate Choices Act" (AB 651) -- modeled on Oregon's law.

<sup>44</sup> Goy, HL, p. 291, Q. 768. (Goy is an assistant professor, Dept. of Psychiatry, School of Medicine, OHSU, and has worked with Dr. Linda Ganzini in surveys dealing with Oregon's assisted-suicide law.)

<sup>45</sup> Farmer, HL, p. 302, Q. 794. (Farmer is Director of Home Care and Manager for Legacy VNA Hospice, part of the Visiting Nurse Association and the Legacy Health System.)

**The CSA can be amended to reflect the intent of Congress**

Congress has never endorsed suicide. Furthermore, it took one step in refusing to facilitate it by passing the Assisted Suicide Funding Restriction Act of 1997 which precludes the use of federal funding for assisted suicide. Under that provision, *federal* funds may not be used for drugs prescribed for the purpose of suicide. Yet, a state can use state dollars for such a purpose.

For example, Oregon pays for drugs for the purpose of suicide. According to Ann Jackson, Executive Director and primary spokesperson of the Oregon Hospice Association, "The State of Oregon, under the Oregon Health Plan, will buy the medications....The drugs are very inexpensive."<sup>46</sup>

Likewise, a determination by Congress that prescribing federally controlled substances for suicide is not a legitimate medical purpose under *federal* law would leave states free to permit physicians to prescribe any of the thousands of medications that are not federally controlled substances for the purpose of suicide.

In *Gonzales*, the U.S. Supreme Court left the door open for Congress to make a determination that prescribing federally controlled substances for suicide is not a legitimate medical purpose.

There is a wealth of data to support a finding by Congress that prescribing controlled substances for suicide is not a legitimate medical purpose under federal law. Note that such a finding would not prevent states from making their own determinations about the *practice* of physician-assisted suicide. That would remain the subject of an ongoing "earnest and profound debate."<sup>47</sup> It would, however, provide the necessary clarification that Congress does not endorse suicide and therefore will not permit *federal* registrations to be used to prescribe *federally* controlled substances for suicide.

A state could still determine what is a legitimate medical *practice* within its borders. However, common sense dictates that, since the federal government issues the registrations for prescribing *federally* controlled substance, it may determine which purposes are not legitimate for the use of such registrations. Indeed, as stated above, the U.S. Supreme Court in *Gonzales* noted that Congress explicitly determines the meaning

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<sup>46</sup> Jackson, HL, p. 307, Q. 819. (Jackson is Executive Director and Chief Executive, Oregon Hospice Association. She is also the primary spokesperson for OHA and Oregon hospices about the Oregon law.)

of a legitimate medical purpose under the CSA.

Thus, Congress may wish to consider making such an explicit determination.

George Orwell said, "Sometimes the first duty of intelligent men is the restatement of the obvious." The following are some pertinent facts regarding suicide in the United States.

- In 1999, David Satcher, MD, then Surgeon General of the United States, declared, "Suicide is a serious public health problem."<sup>48</sup> He noted that suicide was one of the leading causes of mortality in the United States, accounting for nearly 31,000 deaths per year, a number that was more than 50 percent higher than the number of homicides for the same year.<sup>49</sup>
- By 2004, the number of homicides had decreased.<sup>50</sup> However, the number of suicides had increased to 31,647 – more than 86 *per day*<sup>51</sup> – making the annual number of suicides double that of homicides.
- As of 2005, Oregon has experienced an increase in suicides among people who are 65 and older.<sup>52</sup> The rate exceeds the national average and does not include suicides falling under Oregon's assisted-suicide law. According to state epidemiologist Dr. Melvin Kohn, "Suicide is a public health problem."<sup>53</sup> (As noted above, Dr. Kohn, who is a lead author of several of Oregon's official reports on assisted suicide, is not an opponent of assisted suicide.)
- In *Gonzales*, the U.S. Supreme Court, noted that prevention of drug abuse is central to the CSA and that the "undefined term 'drug abuse' is connected with "addiction or abnormal effects on the nervous system."<sup>54</sup> The Court further observed that "to read prescriptions for assisted suicide as constituting 'drug abuse' under the CSA is discordant with the phrase's consistent use throughout the statute, not to mention its ordinary meaning."<sup>55</sup>

Yet, it takes little more than a tremendous grasp of the obvious to recognize that drugs provided for suicide are connected with "abnormal effects on the nervous system,"

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<sup>47</sup> *Washington v. Glucksberg*, 521 U.S. 702, 735 (1997).

<sup>48</sup> U.S. Public Health Service, *The Surgeon General's Call to Action to Prevent Suicide*, (1999), p. 1.

<sup>49</sup> *Id.*

<sup>50</sup> There were 16,137 homicides in 2004. Federal Bureau of Investigation, *Crime in the United States*, (2004), p. 72.

<sup>51</sup> Center for Disease Control, Table 2, Deaths and death rates for 2004. Available at: [http://www.cdc.gov/nchs/data/hesta/preliminarydeaths04\\_tables.pdr#2](http://www.cdc.gov/nchs/data/hesta/preliminarydeaths04_tables.pdr#2) (last accessed Apr. 25, 2006).

<sup>52</sup> Brandon Gee, "Elder suicide has state worried: With Oregon's rate topping the U. S. average, the Department of Human Services readies nine 'strategies of prevention.'" *Oregonian*, Aug. 23 2005.

<sup>53</sup> Mary Ann Albright, "Elder suicide rate high in Oregon," *Corvallis Gazette-Times*, Apr. 7, 2006.

<sup>54</sup> *Gonzales* at 925.

<sup>55</sup> *Id.* at 924.

unless one considers complete shutdown of the nervous system to be a normal effect of prescribed medication.

When Congress amended the CSA in 1984, it did so, in part, to address the frequency with which prescription drugs were involved in drug-induced deaths. Yet Congress did not explicitly state that prescribing drugs for the specific purpose of inducing death posed a threat to public health and safety. It is likely that, at the time, Congress did not envision the possibility that anyone would consider prescribing for suicide to be a legitimate use of a federal registration.

This shortcoming can be remedied easily with relatively minor changes in the CSA. Such changes could be based on finding that:

- (1) Suicide means the act or instance of taking one's own life voluntarily or intentionally.
- (2) Suicide is a public health threat.
- (3) Prescribing federally controlled substances for suicide runs counter to the public interest.
- (4) Congress does not provide federal registrations for the purpose of facilitating suicide and intends that federal registrations not be used for such a purpose.
- (5) Prescribing for the purpose of suicide does not constitute a legitimate medical purpose under the CSA.

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Thank you again for the opportunity to testify before you today. I stand ready to work with the Committee as it continues its consideration of the important issues surrounding the grave public health threat of suicide in the United States.



**Julie S. McMurchie**

**Before the Senate Committee on Judiciary  
Subcommittee on the Constitution, Civil Rights, and Property Rights**

**“The Consequences of Legalized Assisted Suicide and Euthanasia”  
Thursday, May 25, 2006**

I'd like to start out by telling you a little about my mom's background. She grew up on the Philadelphia Main Line, raised by a strict German father and a deaf mother. She was given little independence, and was always told by her parents what to do. She was told to go to Mt. Holyoke College, which she did, and married my father, who went to Harvard Medical School. They immediately had five children. When it came time for my father to decide where to start his practice, they decided to move to Oregon. My mother had never been west of the Mississippi, and moved her entire family across the country based on one picture of the Oregon coast.

My mom loved Oregon. She often talked about the constraints and societal expectations that had burdened her in the East, and how much she loved the free thinkers and independent thought that she found in Oregon. She was intellectual and practical, and raised us all to evaluate and make our own decisions, and to take care of ourselves.

In January of 2000, my 67 year old mother was diagnosed with lung cancer. She had a surgery to remove the tumor, and was pronounced cured, though of course was not. When the tumor returned a few months later, she had another surgery to remove her lung. Each of these surgeries was an enormous undertaking, and she had a great deal of pain and long recoveries. In June of 2000, my mother's sister in Pennsylvania was diagnosed with the same lung cancer. My aunt spent 100 days in a small hospital prior to her natural death. A great deal of that time she was in a coma, and her three sons traveled from Seattle, Florida, and Geneva as much as they could to spend time in that hospital room. My mother and I visited my aunt several times, and it became very clear to my mom that she did not want that death for herself or her family.

In August of 2000, she was diagnosed as terminal, and began talking to her children about hastening her death under Oregon's law. Over the next 4 months she had multiple hospitalizations, ct scans, pet scans, bone scans, chemotherapy and radiation treatments. Also though, she very much continued to make the most of every day. She stayed very active in her book club, her bridge club, and in the lives of her five children and nine grandchildren. I wanted her to come live with me during those last months, but she had no interest in that. She wanted to be independent, and wanted to stay involved in her life.

One morning in December my mom woke up and could not get out of bed because her pain was too great. She was hospitalized for three weeks while we tried to control the pain and get her well enough to fulfill her wishes to go to the Oregon Coast to die. Two of my siblings are physicians married to physicians, and while my parents were divorced at the time of her death, my mother had been married for 40 years to a cardiologist. She had very sophisticated medical and palliative care. She had two MD pain specialists attending her, and had a morphine pump installed directly into her spine. She knew that she could control her pain by increasing her morphine to the point that she would be in a coma, but she did not want that. She wanted to be mentally present in her life, and her children's life, until she died.

I remember very clearly when she made the decision to switch from trying to stay alive, to allowing herself to die. She came home from that hospital stay, and made her first request to hasten her death under Oregon's law. This request was very consistent with my mom's personality, and with the forthrightness and acceptance with which she had treated her illness and terminal diagnosis. All of her five children immediately supported her. After watching this disease ravage her body, and after watching the dignity and grace with which she had handled a terrible year, we all felt she deserved this final bit of control. She remained bedridden and failed rapidly during the fifteen days of the mandatory waiting period. She lost control of her bodily functions, began having difficulty breathing because of the tumors growing in her airways, and began coughing up blood. My sister who is a pulmonologist began to worry that she would hemorrhage in her lungs and drown.

On the morning of January 25<sup>th</sup>, my mom made her final request to end her suffering and use Oregon's Death with Dignity Law. On that morning, she lay in her own bed, in her own home, surrounded by her five children, our five spouses, her remaining sister and a nephew, and her longtime internist and friend. We read some poetry, listened to some music, and she wanted to hear the 23<sup>rd</sup> psalm. We all hugged her, kissed her, and told her how much we loved her. She drank the medication, and fell peacefully into a coma within five minutes. She died 15 minutes after that.

I feel that my family was given a gift that morning. My final memories of my mother are profoundly loving and supportive. May we all be so lucky to die surrounded by those we love most in the world. May we all be so lucky to have the last eyes we see and the last touch we feel to be that of our children.

The inevitability of my Mother's death from her disease was not in question. Her choice to hasten that inevitability was a reflection of her values and emblematic of the personal freedom our country prizes. Her choice was not about making that choice for other's, as in euthanasia, nor was it about compromising the rights of people with disabilities. Her choice in no way demeaned or sought to critique the choices that others with different values make

every day. On the contrary, my Mother would have wanted people with different values, whether grounded in their religion or otherwise, to be able to make their own choices about how their lives come to an end when faced with a terminal diagnosis. Oregon's law is about preserving those choices for everyone.

**Testimony of Hendrik Reitsema**

For

U.S. Senate Judiciary Subcommittee on the Constitution, Civil Rights and Property Rights  
May 25, 2006

Senators, thank you for the privilege of testifying today.

It was January of 1996 that my Dutch grandfather was euthanized in an old peoples home in the North of the Netherlands. My family has never quite been the same since then. Realize that policy relating to life and death issues have massive and far reaching consequences. Since that event in 1996 I have made it a practice to keep abreast of developments surrounding this topic in the Netherlands which is also my home. I hope to share with you a snapshot of what the developments relating to euthanasia policy in the Netherlands have been and how they have effected normal people like myself.

I was visiting my grandfather at the beginning of the week that he was killed unaware - as was also the rest of the family - that a "treatment" of morphine overdose and starvation<sup>1</sup> was being applied to him. My 'Opa' as I called him, being a rather stubborn individual and a very devout Christian man, had had a stroke a couple of years prior to this moment, which resulted in his being partially paralyzed on one side. This resulted in his needing the kind of care that was only available in a home for the elderly. My grandmother who lived two street blocks from the old peoples home visited him every day. Opa was very much the patriarch of our rather sizeable family and was frequently visited by all of us cousins, he was fun to be around. It is very unlikely that this man who loved life so much and was mentally still very much 'with it', would have expressed the desire to die. And yet the medical staff surrounding him was working providing a speedy, dignified and painless death for him as they saw it.

By the mid 1990's this kind of procedure when requested by ailing patients was not at all uncommon in Dutch medical facilities, even though it was not formally legal. Both euthanasia and assisted suicide have been widely practiced in the Netherlands since 1973 although they were against the law until 2002. One needs to understand the Dutch system of professional agreements by specific professions in society with the department of justice so that things can be allowed and monitored even though they are strictly taken illegal. The Dutch situation between 1973 and 2002 was an accumulation of a series of court decisions and medical association guidelines, beginning with a 1973 District Court case in which Geertruida Postma, a Dutch physician, was convicted of the crime of euthanasia after she ended the life of her seriously ill mother.<sup>2</sup> The case led to the reconsideration of the laws against assisted suicide<sup>3</sup> and euthanasia.<sup>4</sup> Though the court found her guilty, they imposed only a one-week suspended sentence and a week's probation. The District's medical inspector in this case set forth certain conditions under which the average physician thought euthanasia should be considered acceptable. Inclusion of those conditions formed the basis for subsequent acceptance of euthanasia and assisted suicide in the Netherlands. These criteria broadly speaking function as the guiding light for the euthanasia legislation in the Netherlands to this day.

The criteria for whether a doctor has acted with due care are as follows<sup>5</sup>:

<sup>1</sup> This is sometimes called 'versterving' in Dutch but this term is most often applied to the cessation of artificial feeding with resultant death for patients who suffer from serious dementia. A research report by E. Fischer of the Free University in Amsterdam which included 276 deaths, indicated that in the three years prior to 1997, 46% of the patients with dementia in that North-Holland nursing home died this way and 22% of the rest.

<sup>2</sup> *Nederlandse Jurisprudentie* 1973, no. 183, District Court of Leeuwarden, 21, February 21, 1973; translation in Walter Lagerway, 3 *Issues in Law and Medicine* 429, 439-42 (1988).

<sup>3</sup> Penal Code of the Netherlands, §294.

<sup>4</sup> Penal Code of the Netherlands, §293.

<sup>5</sup> Euthanasia: A guide to the Dutch Termination of life on Request and Assisted Suicide (Review Procedures) Act. To be found on the web site of the Netherlands department of foreign affairs.

They must:

- a. be satisfied that the patient's request is voluntary and well-considered;
- b. be satisfied that the patient's suffering is unbearable and that there is no prospect of improvement;
- c. inform the patient of his or her situation and further prognosis;
- d. discuss the situation with the patient and come to the joint conclusion that there is no other reasonable solution;
- e. consult at least one other physician with no connection to the case, who must then see the patient and state in writing that the attending physician has satisfied the due care criteria listed in the four points above;
- f. exercise due medical care and attention in terminating the patient's life or assisting in his/her suicide.

My grandfather's case clearly did not meet these criteria very well. The primary reason being that what happened in his treatment was not really being considered euthanasia anymore by the doctors involved, the use of these terms has been a shifting tide. In December of 1995 he was sent to a local hospital for a biopsy on a bump on his gums. The results came back at the beginning of January indicating Non-Hodgkin's lymph cancer. (my sister who is a physician surmised at this point that his prognoses given the age of 80 years old was probably for about 3 years of life). When my grandfather asked for help with pain relief in his thrombotic leg in the following week the house doctor decided to instigate the "treatment" of progressively increased morphine application and subsequent withholding of food to expedite a 'dignified death' and save him from the inevitable suffering which was to come. When I visited him that week I was surprised at how lethargic he was and how lacking his comprehension was. Later that week one of my aunts was visiting him and helping him get some water in when one of the nurses came buy and told her not to do so because it was prolonging the process of dying. This was the first moment that the family realized what was happening. All hell broke loose but we were not successful in reversing the damage done. My grandfather died the next day of pneumonia, which is also the cause of death that the doctors listed on his death certificate. We were not successful to litigate. The impact on all of our family was massive to the degree that it is hard to quantify.

My grandmother felt pressured into agreeing with something she did not comprehend but entrusted into doctors hands as the best treatment, as she had always had much respect for a doctors opinion (research suggests that in 50 % of the cases of euthanasia this is suggested by the physician to the patient.<sup>6</sup>). Moreover my grandfather did not make an explicit request to be killed but asked for help with pain (even the governments own studies<sup>7</sup> show that about 900

<sup>6</sup> Herbert Hendin, "Euthanasia and physician-assisted suicide in the Netherlands," *New England Journal of Medicine*, vol. 336, no. 19 (May 8, 1997), p. 1385, citing van der Maas *et al*, *Euthanasia and other medical decisions concerning the end of life*, (Elsevier, 1992)

<sup>7</sup> In an effort to determine the frequency of assisted suicide and euthanasia, two national studies were undertaken. To obtain the most complete and accurate information, physicians were granted both immunity and anonymity related to their responses. The first study released by the Dutch government on September 10, 1991, found that physician-induced deaths accounted for more than 9.1 percent of annual deaths. Of those deaths, 2,300 were from requested euthanasia, 400 were assisted suicide and 1,040 (an average of approximately 3 per day) died from euthanasia which was administered without the patients' knowledge or consent. Similar results were found in a follow up study five years later: Commissie Onderzoek Medische Praktijk inzake Euthanasie, *Medische Beslissingen Rond Het Levensende*, Sdu Uitgeverij Plantijnstraat (1991), vol. 1, p. 13. The study is popularly known as the "Rommelink Report."

Paul J. van der Maas, *et al*, "Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995," *New England Journal of Medicine*, vol. 335, no. 22 (November 28, 1996), pp. 1699-1705.

cases of euthanasia take place without explicit request.) Also the fact that the logic of the euthanasia protocol is now being applied to infants via the Groninger Protocol<sup>8</sup> which has been taken over by the National Society for Pediatrics and has been agreed to by the ministry of justice, shows that informed consent is not a must in the mind of Dutch physicians. This is a logical consequence of prioritizing the duty to alleviate suffering as the primary task of physicians rather than protecting life.

The fact that his cause of death was not fully reported was also not unique. Although reporting is legally required, almost half of these deaths goes unreported. Moreover because of the distinction between *terminal sedation* and *euthanasia* the number of people where physicians actively aid the dying process is much higher than that which is being called euthanasia in these reports.<sup>9</sup> The legalization of euthanasia<sup>10</sup> which took place fully in April 2002 did not measurably increase the willingness to report. There was actually a drop in reported cases until 2005 while there is not conclusive evidence that there were fewer people killed this way.<sup>11</sup>

The catch 22 that the Dutch legal system has gotten itself into is that if they don't lessen the risk of reporting (i.e. by promising immunity to the physicians) that reporting will not sufficiently take place while not strictly evaluating and applying sanctions means that it is not sufficiently controlled. Moreover the controlling happens after the process of killing has been completed, and this can hardly be considered careful procedure when death which is an irreversible given from the perspective of most of us has already taken place. A policy which does not do better than 40 or 50% reporting rate can hardly be called successful and safe.

I thank you for listening.

#### Appendix 1

##### Cases before the appearance of the Toetsingscommissies (these commissions started in 1998):

1990	486
1995	1.466
1998	2.590

<sup>8</sup> *The Groningen Protocol – Euthanasia in Severely Ill Newborns* NEJM 352:959-962

<sup>9</sup> Dutch doctors are sedating many terminally ill patients until death, in some cases without artificial feeding or hydration. Researchers estimate that terminal sedation occurred in about 10% of the total of deaths in the Netherlands per year, that is 14 000 deaths in 2001 (*Annals of Internal Medicine* 2004;141:178-85). Tony Sheldon *Dutch doctors choose sedation rather than euthanasia* BMJ. 2004;329:368 (14 August), doi:10.1136/bmj.329.7462.368-e

<sup>10</sup> Euthanasia (termination of life on request and assisted suicide) is still a criminal offence, but the Criminal Code has been amended to exempt doctors from criminal liability if they report their actions and show that they have satisfied the due care criteria formulated in the Act. The actions of doctors in such cases are assessed by review committees (appointed by the Minister of Justice and the Minister of Health, Welfare and Sport), which focus in particular on the medical and decision-making procedures followed by the doctor. Where a doctor has reported a case and a review committee has decided on the basis of his report that he has acted with due care, the Public Prosecution Service will not be informed and no further action will be taken

<sup>11</sup> See appendix 1.

**Source:**

G. van der Wal e.a., *Medische besluitvorming aan het einde van het leven – de praktijk en toetsingsprocedure*. pag. 140 Uitgeverij De Tijdstroom – Utrecht 2003

Reported cases by regionale toetsingscommissies:

1999	2.216
2000	2.123
2001	2.054
2002	1.882
2003	1.815
2004	1.886
2005	1.933

**Source:**

*Jaarverslagen regionale Toetsingscommissies*

Cases of euthanasia:

1990	2.700
1995	3.600
2001	3.800

**Source:**

J. Visser, *Plat vlak – levensbeëindigend handelen blijft in omvang gelijk*. In: *Medisch Contact* jrg. 58 nr. 21 pag 842-844 (2003)

G. van der Wal e.a., *Medische besluitvorming aan het einde van het leven – de praktijk en toetsingsprocedure*. pag. 140 Uitgeverij De Tijdstroom – Utrecht 2003

**With these figures it is clear that roughly 40% (and maybe even more of the cases of euthanasia are not reported. This trend is mirrored in the lack of reporting surrounding infanticide in the Netherlands since 1997<sup>12</sup>**

<sup>12</sup> Government-sponsored studies in the 1990s and repeated in 2001 estimated there are 15 to 20 such infant killings in any year. Just 22 cases were reported to the Justice Ministry between 1997 and 2004 - most involving infants with severe damage to the brain and spine from spina bifida - and the ministry decided against prosecuting any of them.  
See also *Ned Tijdschr Geneesk.* 2005 Jan 22;149(4):183-8 *Deliberate termination of life in newborns in The Netherlands; review of all 22 reported cases between 1997 and 2004*

**Testimony of Wesley J. Smith, JD, Before the U.S. Senate Judiciary  
Subcommittee on the Constitution, Civil Rights, & Property Rights,  
May 25, 2006**

Good afternoon. My name is Wesley J. Smith. I am a lawyer, author, and consumer advocate. I am a senior fellow at the Discovery Institute, an attorney and consultant for the International Task Force on Euthanasia and Assisted Suicide, and a special consultant to the Center for Bioethics and Culture.

For more than ten years I have been deeply engaged internationally in public policy debates about the most important bioethical issues facing our nation and global community. These include researching and writing about the ongoing erosion of Hippocratic medical values in bioethics involving areas such as assisted suicide, end of life medical treatment, and other areas of concern. I am the author or coauthor of 11 books, including *Forced Exit: Euthanasia, Assisted Suicide, and the New Duty to Die*, which was first published in 1997 and has just been published in its third edition. I also wrote *Culture of Death: The Assault on Medical Ethics in America*. *Culture of Death* was named "Best Health Book of the Year" at the 2001 Independent Publishers Book Awards. Both books deal substantially with the issue of euthanasia/assisted suicide. My abridged CV is attached to my testimony.

My work in the fields about which I advocate is entirely secular, which I believe is appropriate to the creation of public policy in a nation governed by the rule of law.

I appear today to argue that there is a proper public policy role for the federal government against assisted suicide, such as prohibiting federally controlled substances from being used to intentionally end life, and in the application of other government



policies consistent with the standards of federalism. This would be in keeping with existing federal government policy that already prohibits federal money from being used to fund assisted suicide under the Medicaid program.

There are two deep ideological beliefs asserted by advocates for legalizing assisted suicide. The first is radical individualism that perceives the right of personal autonomy as being virtually absolute. Accordingly, promoters of assisted suicide generally believe that “the individual’s right to self-determination—to control the time, place, and manner of death” is a paramount liberty interest.<sup>1</sup> The second ideological principle underlying assisted suicide advocacy is that killing (ending life) is an acceptable answer to the problem of human suffering.

Assisted suicide is usually couched in terms that would limit assisted suicide to those who are terminally ill. But given the philosophical/ideological principles that underlie the euthanasia movement—that autonomy is paramount and killing is a valid answer to human suffering—restricting assisted suicide to the dying becomes utterly illogical. After all, many people experience far greater suffering and for a far longer period than people who are terminally ill. Thus, once the premises of assisted suicide advocacy become accepted by a broad swath of the medical professions and the public, there is little chance eligibility for “permitted” suicide will remain limited to the terminally ill.<sup>2</sup>

We need only look to the experience of the Netherlands to see the destructive force that the implacable logic of euthanasia ideology unleashes. The Dutch have

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<sup>1</sup> Derek Humphry and Mary Clement, *Freedom to Die: People Politics and the Right-to-Die Movement*, (New York, St. Martin’s Press, 1998), p. 30.

<sup>2</sup> See, for example, Elliot Cohen, Ph.D., “Permitted Suicide: Model Rules for Mental Health Counseling,” *Journal of Mental Health Counseling*, Vol. 23, No. 4, October 2001, pp. 279-294.

permitted euthanasia and assisted suicide since 1973.<sup>3</sup> Euthanasia became an integral part of Dutch medicine after a court ruling that refused to meaningfully punish a physician, Geetruida Postma, who had euthanized her mother.<sup>4</sup> The court accepted the premise—supported by both the prosecution and the defense—that most Dutch doctors favored euthanasia in some cases. Accordingly, even though convicted of murder, Dr. Postma received only a one-week suspended sentence and a year’s probation.

To justify its action, the Court established the first “boundaries” for euthanasia practice in the Netherlands. Among these were the requirements that the patient be considered incurable, implying that the patient must suffer from a severe physical illness; that the patient’s suffering be subjectively unbearable; that the request for termination of life be in writing; and that there should be adequate consultation with other physicians before euthanasia could be carried out.<sup>5</sup> Inclusion of these conditions in the court’s decision became the basis for subsequent public and government acceptance of euthanasia in the Netherlands.

With the Postma decision, the Dutch stepped boldly onto a steep slippery slope. Other court decisions soon followed, with each widening and further liberalizing the conditions under which euthanasia would not be punished. Thus, even though euthanasia remained technically illegal until 2002, it soon became entrenched in Dutch medical practice.

In 1993, the Dutch Parliament formalized the permissive “decriminalized” system of euthanasia permissiveness that had been first crafted by the courts. Under this

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<sup>3</sup> For purposes of this testimony, euthanasia is when a physician lethally injects a patient. Assisted suicide occurs when a physician knowingly provides the lethal means for a patient to commit suicide.

<sup>4</sup> Euthanasia Case Leeuwarden-1973” (Excerpts from court’s decision), trans. Walter Lagerway, *Issues in Law and Medicine* 3 (1988) pp. 429, 439-42.

<sup>5</sup> *Ibid.*

approach, so long as doctors followed the guidelines when euthanizing patients, they would not be prosecuted.<sup>6</sup> These guidelines included:

- The request must be made entirely of the patient's own free will and not under pressure from others.
- The patient must have a lasting longing for death.
- The request must be made repeatedly over a period of time.
- The patient must be experiencing unbearable suffering.
- There must be no reasonable alternatives to relieve suffering than euthanasia.
- Doctors must consult with at least one colleague who has faced the question of euthanasia before.
- Only a doctor can euthanize a patient.
- The euthanasia must be reported to the coroner, with a case history and a statement that the guidelines have been followed.<sup>7</sup>

In actual practice these guidelines were porous and provided scant protection for the weak, vulnerable, and despairing, nor, as we shall see, have they inhibited doctors from euthanizing patients who fell outside the guidelines' parameters.

At this point it is important to recall that when euthanasia was first accepted in the Netherlands, it was supposed to be a rare event, to be resorted to only in the most unusual cases of "intolerable suffering." The guidelines were designed specifically to keep euthanasia occurrences few and far between by establishing demanding conditions that

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<sup>6</sup> "Dutch Parliament Approves Law Permitting Euthanasia," *New York Times*, February 10, 1993.

<sup>7</sup> Carlos Gomez, *Regulating Death*, (1991, Free Press, New York, NY), p. 32.

had to be met, at the risk of criminal prosecution. Over time, however, doctors began to interpret the conditions loosely and even ignore them altogether. In the few circumstances where the law took notice, the courts accommodated expanded euthanasia through continual loosening of the meaning of the guidelines.

This is the typical pattern of the assisted suicide movement. Life-ending actions by doctors are always presented to the public as being advocated as a ‘rare’ occurrence, to be applied only when nothing else can be done to alleviate suffering. Proponents soothingly assure a doubtful public, as the New York euthanasia advocate Dr. Timothy Quill once put it, that assisted suicide will be restricted to “the patient of last resort, [to be] taken only when hospice care stops providing comfort and dignity,” when “all alternatives have been exhausted.”<sup>8</sup> But once accepted widely and put into actual practice—as the Dutch experience clearly demonstrates—it quickly ceases to be rare, nor is killing resorted to only when all else fails. Instead, in the words of the physician, Dr. K. F. Gunning, perhaps the most notable Dutch opponent of euthanasia, “Once you accept killing as a solution for a single problem, you will find tomorrow hundreds of problems for which killing can be seen as a solution.”<sup>9</sup>

Euthanasia was finally formally legalized in the Netherlands in 2001, effective 2002. In the thirty-plus years since euthanasia was redefined in the Netherlands as a legitimate tool of medical practice instead of a serious crime, cultural biases have changed. No longer constrained by conscience or culture, thanks to a redefinition of euthanasia as medical treatment instead of killing, Dutch doctors now terminate categories of people whose assisted deaths would have once provoked outrage, and do so

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<sup>8</sup> Timothy Quill, MD, “Physician Assisted Death: Progress or Peril?”, *Suicide and Life-Threatening Behavior*, 24 No. 4, pp. 315-25, 318.

<sup>9</sup> My interview with Dr. Gunning in preparation for writing *Forced Exit*, October 18, 1995.

in numbers that were not anticipated when the practice was first promoted in 1973. Rather than being rare, statistics show that euthanasia is now almost a matter of medical routine.

### **The Rummelink Report**

In 1990, responding to the ongoing heated debate about Dutch euthanasia and the many anecdotes being told internationally about the involuntary killing of patients by doctors, the Dutch government decided to determine how euthanasia was actually being carried out and appointed an investigative committee for that purpose. Called the Committee to Investigate the Medical Practice Concerning Euthanasia, it was commonly known as the Rummelink Commission, after the committee's chairman, Professor J. Rummelink, then the attorney general of the Dutch Supreme Court.

The commission's two-volume report, known as the Rummelink Report, was issued in 1991.<sup>10</sup> The Rummelink Report included complete statistical data upon which it based its conclusions. Independent analysis of this rich source of information had a profoundly negative impact on the world's view of Dutch euthanasia. According to the Rummelink Report, about 130,000 people die each year in the Netherlands. Of these, approximately 43,300, or about one third, die suddenly—from catastrophic heart attacks, stroke, accidents, etc.—thus precluding medical decision making about end-of-life care.

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<sup>10</sup> J. Rummelink, et al., *Medical Decisions About the End of Life*, in 2 Vols.: *Report of the Committee to Study the Medical Practice Concerning Euthanasia: The Study for the Committee on the Medical Practice Concerning Euthanasia* (the Hague, 1991). Cited hereafter as Rummelink Report I/II.

That leaves approximately 90,000 people whose deaths involve end-of-life medical decision making each year.

With that in mind, here are the figures about euthanasia-related deaths in 1990, derived from the Rummelink Report's published statistical data:

- 2,300 patients were euthanized (killed) by their doctors upon request, and 400 people died through physician-assisted suicide, for a total of 2,700 doctor-induced deaths. That is approximately 3 percent of all deaths involving end-of-life medical care. The equivalent percentage in the United States would be approximately 41,500 deaths.
- 1,040 died from involuntary euthanasia, lethal injections given without request or consent—three deaths every single day. These deaths constitute slightly more than 1 percent of all cases involving end-of-life medical care. (The same percentage in the United States would be approximately 16,000 involuntary killings per year.) Of these involuntary euthanasia cases, 14 percent, or 145, were fully competent to make their own medical decisions but were killed without their request or consent anyway. (The same percentage in the United States would be more than 2,000 who would be killed.) Moreover, 72 percent of the people killed without their consent had never given any indication they would want their lives terminated.
- 8,100 patients died from an intentional overdose of morphine or other pain-control medications, designed primarily to terminate life. In other words, death was not a side effect of treatment to relieve pain, which can

sometimes occur, but was the *intended result* of the overdose. Of these, 61 percent (4,941 patients) were intentionally overdosed without request or consent. The equivalent percentage in the United States would be approximately 78,000.

These figures are startling. Of the approximately 90,000 Dutch people whose deaths involved end-of-life medical decision-making in 1990, 11,140 were intentionally killed (euthanized) or assisted in suicide—or 11.1 percent of all Dutch deaths involving medical decision-making! This is approximately 8.5 percent of Dutch deaths from all causes. Of these killings, *more than half were involuntary* (1,040 involuntary lethal injections and 4,941 involuntary intentional overdoses). Applying those percentages to the U.S. death rate would mean more than 170,000 deaths each year caused by euthanasia or assisted suicide, and about 85,000 of these involuntary, more than the current number of U.S. suicides and homicides combined.

It should also be kept in mind that the Rimmelink statistics probably underestimate the actual number of deaths caused by euthanasia and assisted suicide. A study conducted by the Free University at Amsterdam revealed that two thirds of Dutch general practitioners have certified a patient's death as resulting from natural causes when in fact it was euthanasia or assisted suicide.<sup>11</sup> Another Dutch study arrived at a similar conclusion, finding that only 28 percent of doctors were honest about their euthanasia killings when filling out death certificates.<sup>12</sup> A more recent Dutch study, written up in the *New England Journal of Medicine* in November 1996, found that only

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<sup>11</sup> "Dutch GPs Report Euthanasia as Death by Natural Causes," *British Medical Journal* 304 (February 1992).

<sup>12</sup> P.J. van der Maas, "Euthanasia and Other Medical Decisions Concerning the End of Life," *Health Policy Monographs* 2 (1992), p. 49.

41 percent of all euthanasia deaths were reported to the authorities. This same study revealed that 23 percent of physicians interviewed had killed patients without having received an explicit request.<sup>13</sup> Along a similar vein, a 2003 study published in *The Lancet* found that “the rate of euthanasia had significantly increased” between 1995 and 2001, while “the rate of ending life without a patient’s explicit request remained virtually unchanged.”<sup>14</sup>

### A Practice Beyond Effective Control

In 1999, a statistical analysis of Dutch euthanasia practices published in *Journal of Medical Ethics* concluded that the Dutch promise of “effective regulation ring hollow” and that killing by doctors in the Netherlands “remains beyond effective control.”<sup>15</sup> And for good reason: As University of Haifa’s Raphael Cohen-Almagoran a self-described ideological believer in euthanasia admitted in his 2004 book, *Euthanasia in the Netherlands: The Policy and Practice of Mercy Killing*, Dutch euthanasia policy:

...does not work because all of the guidelines, without exception, are broken time and time again. It is not always the patient who makes the request for euthanasia or physician-assisted suicide. Often the doctor proposes euthanasia to the patient. Sometimes, the family initiates a request. The requirement that the request be voluntary is thus

<sup>13</sup> Fenigsen, “Euthanasia in the Netherlands,” p. 239; and “Special Report from the Netherlands,” *New England Journal of Medicine*, (Nov. 1996), pp. 1699-1711.

<sup>14</sup> Bregie D. Onwuteaka-Phillipsen, et. al., “Euthanasia and Other End-of-Life Decisions in the Netherlands in 1990, 1995, and 2001,” *The Lancet*, Vol. 302, August 2, 2003.

<sup>15</sup> Henk Jochemsen and John Keown, *Journal of Medical Ethics*, 1999; 25: 16-21.



compromised. On occasion, the patient's request is not well considered...[T]here have been cases in which no request was made and patients were put to death. Furthermore, the patient's request is not always durable and persistent as required.<sup>16</sup>

Beginning with the Rummelink Report and continuing thereafter with virtually every other study of Dutch euthanasia practices—whether by proponents or opponents of medicalized killing—report after report has demonstrated clearly that guidelines do not protect and do not restrict. And why should they? The Dutch government has clearly indicated it has no interest in forcing doctors to toe the line by its infrequent prosecution of doctors who violate euthanasia regulations, and in the rare case of a conviction, never imposing meaningful punishment. For example, the *British Medical Journal* reported on a general practitioner who killed his elderly comatose patient with a lethal injection, was convicted of murder but received a one week suspended sentence, hardly a meaningful penalty despite having violated virtually every protective guideline.<sup>17</sup>

But the issue goes much deeper than law enforcement authorities refusing to enforce the rules. What euthanasia really did to the Dutch was to profoundly alter the nation's conception of right and wrong. With the widespread acceptance of a euthanasia consciousness in the Netherlands, the guideline limitations became mere window dressing that made little actual difference at the bedside to doctors or, indeed, to much of the general public. Finding the proverbial exception to the rule became a standard

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<sup>16</sup> Raphael Cohen-Almagor, *Euthanasia in the Netherlands: The Policy and Practice of Mercy Killing*, Dordrecht, Kluwer Academic Publishers, 2004), p. 176.

<sup>17</sup> Tony Sheldon, "Dutch GP Found Guilty of Murder Faces No Penalty," *British Medical Journal*, March 3, 2001.

practice, which in turn, soon changed the exception into the rule. The official guidelines then expanded to meet the actual practice.

The psychiatrist Dr. Herbert Hendin, medical director of the American Foundation for Suicide Prevention, is one of the world's foremost experts on Dutch euthanasia. Over the last several years, Hendin has held extensive discussions with Dutch doctors who euthanize patients and has reviewed the records of actual cases. Dr. Hendin believes that many doctors in the Netherlands feel justified in performing involuntary euthanasia, because a system that accepts killing as a legitimate medical practice "encourages some to feel entitled to make [euthanasia] decisions without consulting the patient."<sup>18</sup> As an example, Hendin recounts his interview with a pro-euthanasia doctor who justified killing a nun who had requested not to be killed on the basis of religious belief, because *he felt* she was in too much pain.<sup>19</sup>

To prove the existence of cases that violate the official guidelines, it is not necessary to rely on anecdotal evidence. Such cases have even been documented in euthanasia-friendly documentaries originally produced in the Netherlands and later shown in the United States. One such documentary, broadcast over public television on the program *The Health Quarterly* in 1993, revealed how broadly the Dutch guidelines are interpreted.<sup>20</sup>

One case documented in the film concerns a man named Henk Dykema, who at the time of filming was asymptomatic HIV-positive. Dykema feared the afflictions that he expected to befall him and had been asking his doctor to kill him for more than a year.

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<sup>18</sup> Herbert Hendin, MD, "Assisted Suicide, Euthanasia, and Suicide Prevention: The Implications of the Dutch Experience," *Suicide and Life Threatening Behavior*, 25 (1), Spring 1995, p. 202.

<sup>19</sup> *Ibid.* pp. 202-02.

<sup>20</sup> "Choosing Death," *The Healthcare Quarterly*, WGBH-Boston, aired March 23, 1993.

The film shows the doctor telling Dykema that he might live for years at his current stage of infection, but the patient wants none of it. The doctor, a general practitioner, then discussed Dykema's case with a colleague, also a general practitioner. Significantly, no psychiatrist was consulted or involved. Finally, the doctor agreed to provide a poisonous drug cocktail to Dykema, even though he was not suffering any significant physical symptoms.

Dykema's assisted suicide was clearly not a last resort, as required by the Dutch guidelines. He and his doctor did not explore all other possible options, such as psychiatric treatment, which could well have alleviated his anxiety and depression. Nor was he told of the actions the doctor could have taken to relieve his suffering when he did become ill. The doctor didn't even wait until his patient had actual symptoms of AIDS.

Dr. Hendin, analyzing Dykema's case from a psychiatrist's perspective, commented, "The patient was clearly depressed. The doctor kept establishing that the man was persistent in his request, but did not address the terror that underlay it."<sup>21</sup> Now consider this: had the doctor called in suicide prevention experts to help Dykema instead of assisting his suicide, Dykema might well have survived long enough to benefit from the drugs that now extend the lives of HIV patient for many years.

The documentary also shows Maria, a twenty-five-year-old woman with anorexia nervosa, asking for euthanasia. She is in remission but fears a recurrence of her malady, stating: "I've thought about dying day and night, and I know that if relief does not come, I will return to the old pattern, the pattern of self-punishment, hurting myself I know it. I feel it, and therefore I hope the release will come soon and I die." Maria's doctor agrees

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<sup>21</sup> Hendin, "Assisted Suicide, Euthanasia, and Suicide Prevention," p. 197.

to assist her suicide, justifying his abandoning his patient to her worst fears, "It is not possible to have a good quality of life for her." This case was even too much for the authorities, who brought charges against the doctor. However, the euthanasia consciousness had so permeated the justice system that a judge ruled that Maria's assisted suicide was justified because her suffering had made her life unbearable.

Similar tragedies can be found in many published investigations of Dutch euthanasia. For example, *The Oregonian* reported on a woman with skin cancer who was euthanized. She was not in pain, nor was she in a terminal stage of her illness. Rather, she was upset by the scars on her face and demanded euthanasia from her doctor, or else—the threat being that she would "jump from the balcony." Her doctor, to his later expressed regret, accommodated her wish to die.<sup>22</sup>

Studies indicate that families, rather than patients, sometimes decide when the time has come for euthanasia. According to Dr. Hendin, doctors called in such cases "usually advocate euthanasia," because they "support the relatives' desire to be free from the burden of caring for the patient."<sup>23</sup> One such case occurred when a wife told her husband to choose euthanasia or a nursing home. Not wanting to be cared for by strangers, he chose death. The doctor killed him, despite knowing of the coercion.<sup>24</sup>

*Dancing With Mr. D*, a revealing book written a few years ago by a Dutch doctor, Bert Keizer, demonstrated how farcical the protective guidelines have become in the Netherlands. Keizer works in a nursing home, where he cares for—and sometimes kills—disabled, elderly, and dying people. He looks upon euthanasia as a necessary and

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<sup>22</sup> Mark O'Keefe, "The Dutch Way of Doctoring," *The Oregonian*, January 9, 1995.

<sup>23</sup> Herbert Hendin, "Dying of Resentment," *New York Times*, January 9, 1995.

<sup>24</sup> *Id.*

proper, albeit distasteful, part of his job. As depicted in the book, so do his colleagues, patients, and their families.

Keizer is brutally honest in revealing his own attitudes about his patients. He depicts the lives of frail and dying people as pointless, useless, ugly, grotesque. Those with whom Keizer interacts all seem to share these views, including his colleagues, family members of patients, and the patients themselves. This allows Keizer to kill patients without consequence other than having a few bad dreams.

And kill his patients Keizer does, again and again. One man he euthanizes probably has lung cancer but the diagnosis is never certain. A relative tells Keizer that the man wants to be given a lethal injection, a request later confirmed by the patient. Keizer quickly agrees to kill the man. Demonstrating the utter uselessness of “protective guidelines,” Keizer never tells his patient about treatment options or how the pain and other symptoms of cancer can be palliated effectively. He never checks to see if the man has been pressured into wanting a hastened death or is depressed. Keizer doesn’t even bother to confirm the diagnosis with certainty. When a colleague asks why rush, and points out that the man isn’t suffering terribly, Keizer’s radical view of autonomy and his acceptance of killing as an answer to serious human illness, leads him to snap irritably:

Is it for us to answer this question? All I know is that he wants to die more or less upright and that he doesn’t want to crawl to his grave the way a dog crawls howling to the side walk after he’s been hit by a car.<sup>25</sup>

Another of Keizer’s patients is disabled by Parkinson’s disease. The patient requests to be killed, but before the euthanasia can be carried out, he receives a letter

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<sup>25</sup> Bert Keizer, *Dancing With Mr. D: Notes on Life and Death*, (1996, Doubleday, New York, NY), p. 37.

from his brother, who uses a religious argument to urge him to change his mind. The letter causes the man to hesitate, upsetting Keizer, who writes:

I don't know what to do with such a wavering death wish. It's getting on my nerves. Does he want to die or doesn't he? I do hope we won't have to go over the whole business again, right from the very start.<sup>26</sup>

Keizer involves the nursing home chaplain to assure the man that euthanasia will not upset God. The man again thinks he wants to die. Keizer is quick with the lethal injection, happy the man has "good veins," and the man expires before his uncertainty can disturb his doctor's mood again.

Dutch doctors now also assist the suicides of depressed people who are not physically ill—and the practice was approved explicitly by the Dutch Supreme Court in the death of Hilly Bosscher. Bosscher wanted to kill herself because she had lost her two sons—one to suicide in 1986 and the other to brain cancer in 1991. Bosscher had briefly received psychiatric treatment years earlier for the depression and suicidal thoughts she experienced after her son's suicide. On the day her second son died, she failed in an attempt to kill herself. She still wanted to die but hesitated at unassisted self-destruction for fear that she would be hospitalized if she tried and failed again. However, she moved the graves of her two sons to the same cemetery and purchased a burial plot for herself so that she could be buried between them.<sup>27</sup>

Bosscher began to attend meetings of the Dutch Euthanasia Society, where she met Dr. Boudewijn Chabot. She told Chabot that she didn't want therapy, "because it

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<sup>26</sup> Ibid. p. 94.

<sup>27</sup> Gene Kaufman, "State v. Chabot: A Euthanasia Case Note," *Ohio Northern University Law Review*, 20 No. 3 (1994), p. 816-17.

would loosen the bonds with her deceased sons.”<sup>28</sup> Chabot took her as a patient anyway and met with her on four occasions between August 2 and September 7, 1991. Chabot did not attempt to treat her. Rather, he interviewed her to determine her prognosis. After these interviews and his consultations, believing her to be suffering from “incurable grief”—and despite the complete absence of any physical illness—he helped Bosscher kill herself on September 28, 1991.<sup>29</sup>

Chabot was prosecuted, although it was never contemplated that he would be jailed or otherwise meaningfully punished.<sup>30</sup> Indeed, the government’s own witness supported the assisted suicide.<sup>31</sup> The Dutch Supreme Court, with the minor caveat that Chabot erred by not having a colleague independently examine the patient, validated Chabot’s actions. The basis of the ruling was that the law cannot distinguish between suffering caused by physical illness and suffering caused by mental anguish—which, of course, is where euthanasia leads with the sheer force of logic.

#### **Dutch Euthanasia Leads to Permitted Infanticide**

In the Netherlands, infants are killed because they have birth defects, and doctors justify the practice. A 1997 study published in the British medical journal, *The Lancet*, revealed how deeply pediatric euthanasia had metastasized into Dutch neonatal medical practice. According to the report, doctors killed approximately 8 percent of all infants

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<sup>28</sup> Id. P. 817.

<sup>29</sup> Kathleen Foley and Herbert Hendin, *The Case Against Assisted Suicide*, (Baltimore, Johns Hopkins University Press, 2002), p. 110.

<sup>30</sup> Wesley J. Smith, *Forced Exit: Euthanasia, Assisted Suicide, and the New Duty to Die*, (New York, Encounter Books, 2006), p. 118.

<sup>31</sup> Foley, Hendin, *The Case Against Assisted Suicide*, p. 110.

who died in the Netherlands in 1995. Assuming this to be typical, this amounts to approximately 80-90 infanticides per year. Of these, one-third would have lived more than a month. At least 10-15 of these killings involve infants who did not depend on life-sustaining treatment to stay alive. The study found that 45 percent of neonatologists and 31 percent of pediatricians, who responded to study's questionnaires, had killed infants.<sup>32</sup> A follow up study of end-of-life decisions made for infants published in the April 9, 2005, found that nothing had changed. In 2001, "in 8%" of cases, drugs were administered to infants "with the explicit intention to hasten death."<sup>33</sup>

In 2004, Groningen University Medical Center made international headlines when it admitted to permitting pediatric euthanasia and published the "Groningen Protocol," infanticide guidelines the hospital utilized when killing 15-20 disabled newborns each year.<sup>34</sup> The Protocol creates three categories of killable infants: infants "with no chance of survival," infants with a "poor prognosis and are dependent on intensive care," and "infants with a hopeless prognosis," including those "not depending on intensive medical treatment but for whom a very poor quality of life...is predicted."<sup>35</sup> Par for the course, authorities refused to prosecute even though pediatric infanticide is clearly murder under Dutch law.

Apologists for the infanticide applauded Dutch doctors for going public with the Protocol. "As things are," Eduard Verhagen, head of Groningen's children's clinic told

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<sup>32</sup> Agnes van der Heide, et. al., "Medical End-of-Life Decisions Made for Neonates and Infants in the Netherlands," *The Lancet*, 350, 1997.

<sup>33</sup> Astrid M. Vrakking, et. al., "Medical End-of-Life Decisions Made for Neonates and Infants in the Netherlands, 1995-2001," *The Lancet*, Vol. 365, April 9, 2005.

<sup>34</sup> "No Prosecution for Dutch Baby Euthanasia," Reuters, January 22, 2005.

<sup>35</sup> Eduard Verhagen and Peter J. J. Sauer, "The Groningen Protocol—Euthanasia in Severely Ill Newborns," *New England Journal of Medicine*, Marcy 10, 2005.



the Associated Press, “people are doing this secretly and that is wrong. In the Netherlands we want to expose everything to let everything be subject to vetting.”<sup>36</sup>

Contrary to Dr. Verhagan’s assertion, it has long been known Dutch doctors kill disabled and dying babies—as *The Lancet* study of 1995 infanticides (published in 1997) cited above demonstrates. Indeed, a 1990 report of the Royal Dutch Medical Association (KNMG), *Life-Terminating Actions with Incompetent Patients*, set forth “requirements for careful medical practice” when ending the lives of handicapped newborns. The standard for permitting pediatric euthanasia was based on what Dutch doctors call an “unlivable life.”<sup>37</sup> Rita Marker discussed Dutch infanticide in her seminal expose of the international euthanasia movement, *Deadly Compassion*.<sup>38</sup> I also wrote about Dutch infanticide practices in my 1997 edition of *Forced Exit*.<sup>39</sup>

Infants are not the only children who are eligible for euthanasia. Pediatric oncologists have provided a *hulp bij zelfoding* (self-help for ending life) program for adolescents since the 1980s, in which poisonous doses are prescribed for minors with terminal illness.<sup>40</sup> Moreover, children who want physician-assisted death may be able to receive it without consent of their parents.<sup>41</sup> Dutch euthanasia advocates have also agitated to reduce the age of consent to euthanasia to 12-year-olds.

<sup>36</sup> “Netherlands Hospital Euthanizes Babies,” Associated Press, November 30, 2004.

<sup>37</sup> “Report of the Dutch Royal Society of Medicine: Life-Terminating Actions with Incompetent Patients,” Part I, “Severely Handicapped Newborns,” *Issues in Law and Medicine* 8, No. 2 (1992).

<sup>38</sup> Rita Marker, *Deadly Compassion: The Death of Ann Humphry and the Truth About Euthanasia*, (New York, William Morrow, 1993).

<sup>39</sup> Wesley J. Smith, *Forced Exit: The Slippery Slope from Assisted Suicide to Legalized Murder*, (New York, Times Books, 1997).

<sup>40</sup> G. G. Humphrey, Letters to the Editor, *Journal of American Medicine*, 260 (1988) p. 788.

<sup>41</sup> Royal Dutch Medical Association, *Vision of Euthanasia* (1986, Royal Dutch Medical Association, the Hague, Netherlands), p. 14.

**Drawing Conclusions**

Unlike the Dutch, Americans do not come to the decision whether to accept legalized assisted suicide blindly. We have the Dutch experience to guide us. On the basis of their experience with euthanasia, what can we learn? First, the slippery slope is very real. As Dr. Gunning put it, the Dutch have proved that once killing is accepted as a solution for one problem, tomorrow it will be seen as the solution for hundreds of problems. Once we accept the killing of terminally ill patients, as did the Dutch, we will invariably, over time, accept the killing of chronically ill patients, depressed patients, and ultimately perhaps, even children.

Second, adopting killing as an acceptable answer to human suffering eventually changes popular outlooks. The law not only reflects our values, but in our diverse age, it tells us right from wrong. Accordingly, once killing is redefined as medical treatment, it becomes transformed from “bad” into “good.” Thus, the guidelines intended to “protect against abuse” eventually are viewed not as protections but instead as hurdles separating sick and dying patients from the beneficence of death. In such an intellectual and cultural milieu, it becomes easy to justify ignoring or violating “guidelines.”

Third, the Netherlands is a much more tolerant society than we are, generally more accepting of differences among people, such as those of race, gender, and sexual orientation. An editorial in the *New England Journal of Medicine* cited a plethora of studies that uncovered significant race-based inequality in the delivery of health care in the United States, and opined that the disparities in the delivery of health care apparently

caused by racism need to be focused upon with the “rigor and attention given to other health concerns of similar magnitude.”<sup>42</sup> These and other factors make it likely that legalizing and especially “routinizing” euthanasia in the United States would be especially dangerous for marginalized populations.

Finally, the euthanasia virus is catching. A 2000 report found that 10 percent of Belgian deaths appear to result from euthanasia.<sup>43</sup> With Belgian doctors clearly eager to follow the lead of their Dutch neighbor, Belgium formally legalized euthanasia in 2002. Notably, the first Belgian case, the killing of a man with multiple sclerosis, violated the guidelines; and just as occurs routinely in the Netherlands, the doctor involved faced no consequences. Now Belgium is set to legalize euthanasia for children. Indeed, Belgian doctors in Flanders have been found to commit infanticide in about the same numbers as their Dutch counterparts. Moreover, according to a study published in *The Lancet*, nearly 70% “of the physicians questioned...had either used lethal drugs for this purpose [to end infants’ lives] or could conceive of situations in which they would use them.”<sup>44</sup>

Given the profound import of the debate over assisted suicide, the federal government has a crucial role to play. By pursuing its own national public policy that unequivocally opposes transforming suicide and euthanasia, it can influence the national debate without infringing on important principles of federalism. Such policies could include enacting a statute declaring suicide not to be a legitimate medical use of federally controlled substances. It can broaden the prohibition of using federal funds for use in

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<sup>42</sup> H. Jack Gleiger, MD, editorial, “Race and Health Care—An American Dilemma,” *New England Journal of Medicine*, 335, No. 11 (1996.)

<sup>43</sup> BBC News, “Doctors ‘Help Kill One in Ten Belgians,” November 24, 2000.

<sup>44</sup> Veerle Provoost, et. al., “Medical End-of-Life Decisions in Neonates and Infants in Flanders,” *The Lancet*, Vol. 365, April 9, 2005.

assisted suicide, under Medicaid, Medicare, in Veterans hospitals, and the like. Engaging the issue at the federal level would be consistent with the government's obligation to promote the general welfare and I urge the Senate to explore this important issue fully toward achieving these ends.

**Testimony of Kathryn Tucker**

**Director of Legal Affairs  
Compassion & Choices  
Affiliate Professor of Law  
University of Washington School of Law  
Seattle University School of Law**

**Before the Senate Committee on Judiciary  
Subcommittee on the Constitution, Civil Rights, and Property Rights**

**“The Consequences of Legalized Assisted Suicide and Euthanasia”  
Thursday, May 25, 2006**

**I. INTRODUCTION**

Members of the Committee, Good Afternoon. Thank you for inviting me to testify in this important hearing today. As Legal Director for Compassion & Choices, I speak on behalf of our supporters, who strongly believe, as do a majority of Americans, that dying patients should be empowered to control their dying process. Even with excellent pain and symptom control a fraction of dying patients will confront a dying process so prolonged and marked by such extreme suffering and deterioration, that they determine that hastening impending death is the least worst alternative.

I have some specialized expertise that I hope will be of use to this committee. I represented the patients and physicians in the cases *Glucksberg v. Washington*<sup>1</sup> and *Quill v. N.Y.*,<sup>2</sup> decided by the US Supreme Court in 1997, and represented the patients in the case decided by the Court just this Term, *Gonzales v. Oregon*.<sup>3</sup>

The *Glucksberg* and *Quill* cases were brought by terminally ill patients and physicians in Washington and New York against those States, challenging state law criminalizing “assisted suicide”, to the extent that such statutes could be deemed applicable to mentally competent terminally ill patients who desired to hasten impending death.<sup>4</sup> The plaintiffs claimed that the right to make this choice was protected under the federal constitution’s guarantees of liberty and equality. These claims, successful in both federal Courts of Appeals, the Second and Ninth Circuits, were rebuffed by the US Supreme Court in 1997, because the Court believed that the issue should be addressed, in the first instance, by the states.<sup>5</sup> The Court’s decision encouraged the “earnest and profound debate about the morality, legality and practicality of physician assisted suicide” to continue.<sup>6</sup>

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<sup>1</sup> *Washington v. Glucksberg*, 521 U.S. 702, 117 S. Ct. 2258, 138 L. Ed. 2d 772 (1997).

<sup>2</sup> 521 U.S. 793 (1997).

<sup>3</sup> *Gonzales v. Oregon*, 126 S.Ct. 904 (2006).

<sup>4</sup> *Washington v. Glucksberg*, 521 U.S. 702, 117 S. Ct. 2258, 138 L. Ed. 2d 772 (1997) (citing *Compassion in Dying v. Washington*, 850 F. Supp. 1454 (W.D. Wash 1994).

<sup>5</sup>Supra notes 1 and 2.

<sup>6</sup> *Washington v. Glucksberg*, 521 U.S. 702, 735, 117 S. Ct. 2258, 2275, 138 L. Ed. 2d 772 (1997). In *Gonzales v. Oregon*, 126 S.Ct. 904, U.S., 2006, the Court again recently noted “The

More than eight years of experience in the state of Oregon has demonstrated that risks to patients are not realized when a carefully drafted law is in place.<sup>7</sup> In light of the Oregon experience, even previously staunch opponents have recognized that continued opposition to such a law can only be based on personal moral or religious grounds.<sup>8</sup> The State of Vermont recently concluded, after thorough review of the Oregon experience, that: **“it is [quite] apparent from credible sources in and out of Oregon that the Death with Dignity Act has not had an adverse impact on end-of-life care and in all probability has enhanced the other options.”**<sup>9</sup>

Arthur Caplan, Director of the Center for Bioethics at the University of Pennsylvania School of Medicine, after reviewing the Oregon data stated: “I was worried about people being pressured to do this. But this data confirms, for the seventh year, that the policy in Oregon is working. There is no evidence of abuse or coercion or misuse of the policy.”<sup>10</sup>

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importance of the issue of physician-assisted suicide, which has been the subject of an “earnest and profound debate” across the country, Glucksberg, 521 U.S., at 735, 117 S.Ct. 2258, . . .” At 921.

<sup>7</sup> For a recent comprehensive overview of the Oregon experience see Timothy E. Quill, M.D., and Christine K. Cassel, M.D., *Professional Organizations' Position Statements on Physician-Assisted Suicide: A Case for Studied Neutrality*, *Annals of Internal Medicine*, vol. 138(3), pp. 208-11 (Feb. 2003). See also Linda Ganzini, M.D., et al., *Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death With Dignity Act*, 285 *JAMA* 2363-69 (May 9, 2001); M.A. Lee & S.W. Tolle, *Oregon's Assisted Suicide Vote: The Silver Lining*, 124 *ANNALS OF INTERNAL MED.* 267, 267-69 (1996).

<sup>8</sup> See Daniel Lee, *Physician-Assisted Suicide: A Conservative Critique of Intervention*, *HASTINGS CTR. REPORT* at 17-19 (2003).

<sup>9</sup> “Oregon's Death With Dignity Law and Euthanasia in the Netherlands: *Factual Disputes, 2004*” at p.30 ([http://www.leg.state.vt.us/reports/04Death/Death\\_With\\_Dignity\\_Report.htm](http://www.leg.state.vt.us/reports/04Death/Death_With_Dignity_Report.htm)).

<sup>10</sup> William McCall, AP writer, *Columbian*, Mar 11, 2005, pg. C.2.

The American Public Health Association, in an amicus brief filed in the Supreme Court of the United States recently, advised the Court:

Researchers have consistently found that experience in Oregon *does not* bear out concerns that physician-assistance 'would be disproportionately chosen by or forced on terminally ill patients who were poor, uneducated, uninsured, or fearful of the financial consequences of their illness.'<sup>11</sup>

## II. OVERVIEW OF OREGON LAW AND EXPERIENCE WITH IMPLEMENTATION:

### A. Passage and Challenges

The Oregon Death with Dignity Act ("Dignity Act") was passed in 1994 through the initiative process.<sup>12</sup> Opponents of the Dignity Act have worked since then to overturn this law. First they sought relief from the Federal Government, urging the Drug Enforcement Administration ("DEA") to take action against Oregon physicians who acted in compliance with the law on the basis that such activity violates the Controlled Substances Act ("CSA").<sup>13</sup>

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<sup>11</sup> *Gonzales v. Oregon*, No. 04-623, [http://www.drugpolicy.org/docUploads/APHA\\_Oregon\\_brief2004.pdf](http://www.drugpolicy.org/docUploads/APHA_Oregon_brief2004.pdf) At p. 18. (emphasis in original; quoting Chin et al. and Hedberg reports published in the NEJM).

<sup>12</sup> Implementation was obstructed for several years by a lawsuit brought by opponents who argued that a law permitting terminally ill patients to choose physician assistance in dying denied the terminally ill equal protection of the laws. The Ninth Circuit dismissed the case on the grounds that the plaintiffs lacked standing. *Lee v. Oregon*, 891 F. Supp. 1429 (D. Or. 1995), *vacated*, 107 F.3d 1382 (9th Cir. 1997).

<sup>13</sup> See generally Timothy Egan, *Threat from Washington Has Chilling Effect on Oregon Law Allowing Assisted Suicide*, N.Y. TIMES, Nov. 19, 1997, at A18.



The DEA initially opined that its agents could revoke the registrations of physicians who assisted in hastening deaths under the DIGNITY ACT. U.S. Attorney General Janet Reno, however, overruled this position, concluding that the CSA did not reach such conduct.<sup>14</sup> Opponents then sought, in two successive sessions of Congress, to amend the CSA to expand its scope to reach the DIGNITY ACT.<sup>15</sup> Both efforts failed in the face of strong opposition from the medical community founded on the concern that the proposed measures would exacerbate physicians' fears regarding the use of controlled substances in pain management.<sup>16</sup>

A change in federal administration and philosophy led to a change in legal interpretation. The Bush Administration's first Attorney General, John Ashcroft, issued a Directive on November 6, 2001 (the "Ashcroft Directive"),

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<sup>14</sup> In an opinion letter, Reno stated that "[t]he Department has conducted a thorough and careful review of the issue . . . [and] has concluded that adverse action against a physician who has assisted in a suicide in full compliance with the Oregon Act would not be authorized by the CSA." Statement of Attorney General Reno on Oregon's Death with Dignity Act, U.S. Dept. of Justice, June 5, 1998. Reno concluded that "[t]here is no evidence that Congress, in the CSA, intended to displace the states as the primary regulators of the medical profession, or to override a state's determination as to what constitutes legitimate medical practice in the absence of a federal law prohibiting that practice." *Id.*

<sup>15</sup> The Lethal Drug Abuse Prevention Act of 1998, H.R. 4006, 105th Cong. (1998) and The Pain Relief Promotion Act of 1999, H.R. 2260, 106th Cong. (1999).

<sup>16</sup> See Marcia Angell, *Caring for the Dying Congressional Mischief*, 341 *NEW ENG. J. MED.* 1923 (1999) ("If the bill becomes law, it will almost certainly discourage doctors from prescribing or administering adequate doses of drugs to relieve the symptoms of dying patients."); David Orentlicher & Arthur Caplan, *The Pain Relief Promotion Act of 1999, A Serious Threat to Palliative Care*, 283 *JAMA* 255 (2000) ("[P]rogress [in the area of improved pain care] may be dealt a severe setback should Congress decide to enact the [PRPA] of 1999 . . . . [T]he most likely effect of PRPA would be to discourage physicians nationwide from adequately treating the suffering of their dying patients.").

advising that the Department of Justice had concluded that prescribing controlled substances under the DIGNITY ACT violated the CSA<sup>17</sup>.

The Ashcroft Directive was challenged in federal court by the state of Oregon, an Oregon physician and pharmacist, and a group of terminally ill Oregonians, who asserted that it violated the CSA, the Administrative Procedure Act and the U.S. Constitution. The federal district court, the Ninth Circuit Court of Appeals, and the United States Supreme Court all concluded that the Directive exceeded the authority granted under the CSA, and a permanent injunction was entered.<sup>18</sup> The Supreme Court held that the Attorney General did not have the authority to effect a “radical shift” in the balance of state-federal power as it pertains to the regulation of the practice of medicine. The Court reaffirmed the traditional state-federal balance of power in regulating the practice of medicine, specifically upholding Oregon’s physician-assisted dying law as a legitimate regulation of medicine.<sup>19</sup> By noting that

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<sup>17</sup> A.G. Order No. 2534-2001, 66 Fed. Reg. 56,607 (Nov. 9, 2001)( finding that “assisting suicide is not a ‘legitimate medical purpose’ within the meaning of 21 C.F.R. § 1306.04 (2001)” and “prescribing, dispensing, or administering federally controlled substances to assist suicide violates the [CSA]. In particular, “[s]uch conduct by a physician registered to dispense controlled substances may ‘render his registration . . . inconsistent with the public interest’ and therefore subject to possible suspension or revocation under 21 U.S.C. § 824(a)(4).”

<sup>18</sup> 126 S. Ct. 904 (2006); 368 F.3d 1118 (9th Cir. 2004); 192 F. Supp. 2d 1077(D. Or. 2002).

<sup>19</sup> “In deciding whether the CSA can be read as prohibiting physician-assisted suicide, we look to the statute’s text and design. The statute and our case law amply support the conclusion that Congress regulates medical practice insofar as it bars doctors from using their prescription-writing powers as a means to engage in illicit drug dealing and trafficking as conventionally understood. Beyond this, however, the statute manifests no intent to regulate the practice of medicine generally. The silence is understandable given the structure and limitations of federalism, which allow the

General Ashcroft's view of physician-assisted dying was but "one reasonable understanding of medical practice," the Court made clear that Oregon's view also is reasonable.<sup>20</sup>

**B. Implementation of the Oregon Law**

The DIGNITY ACT establishes tightly controlled procedures under which competent, terminally ill adults who are under the care of an attending physician may obtain a prescription for medication to allow them to control the time, place, and manner of their own impending death.<sup>21</sup> The attending physician must determine, among other things, that the patient is mentally competent, an Oregon resident, and confirm their diagnosis and prognosis.<sup>22</sup> To qualify as "terminally ill" a person must have "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months."<sup>23</sup>

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States " 'great latitude under their police powers to legislate as to the protection of the lives, limbs, health, comfort, and quiet of all persons.' "(citations omitted.) The structure and operation of the CSA presume and rely upon a functioning medical profession regulated under the States' police powers." *Gonzales v. Oregon*, 126 S.Ct. 904, U.S., 2006, p. 922-923.

<sup>20</sup> "The primary problem with the Government's argument, however, is its assumption that the CSA impliedly authorizes an Executive officer to bar a use simply because it may be inconsistent with one reasonable understanding of medical practice." *Gonzales v. Oregon*, 126 S.Ct. 904, U.S., 2006, p. 924.

<sup>21</sup> Or. Rev. Stat. § 127.805.

<sup>22</sup> Or. Rev. Stat. § 127.815.

<sup>23</sup> Or. Rev. Stat. § 127.800(12).

The attending physician must also inform persons requesting such medication of their diagnosis and prognosis, the risks and probable results of taking the medication, and alternatives to taking their own lives, including, but not limited to, hospice care and pain relief.<sup>24</sup> A consulting physician must confirm the attending physician's medical opinion.<sup>25</sup>

Once a request from a qualifying patient has been properly documented and witnessed, and all waiting periods have expired, the attending physician may prescribe, but not administer, medication to enable the patient to end his or her life in a humane and dignified manner. The DIGNITY ACT immunizes physicians and pharmacists who act in compliance with its comprehensive procedures from civil or criminal sanctions, and any professional disciplinary actions based on that conduct.

The DIGNITY ACT also requires healthcare providers to file reports with the State documenting their actions<sup>26</sup>; thus, Oregon's experience with legal physician-assisted dying has been extensively documented and studied. To date, the Oregon Health Division and/or the Oregon Department of Human Service Office of Disease Prevention and Epidemiology have issued eight annual reports that present and evaluate the state's experience with the DIGNITY ACT.<sup>27</sup> Related reports and articles have also been published in

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<sup>24</sup> Or. Rev. Stat. § 127.800(7).

<sup>25</sup> Or. Rev. Stat. § 127.800(8).

<sup>26</sup> Or. Rev. Stat. § 127.865.

<sup>27</sup> Each of these annual reports is available at the Oregon Department of Human Services website, <http://www.ohd.hr.state.or.us/chs/pas/pas.cfm>.

leadings medical journals.<sup>28</sup> These reports constitute the only actual source of reliable data regarding the experience of legal, regulated physician-assisted dying in America.

These reports have shown the dire predictions of those initially opposed to the DIGNITY ACT to be baseless. The data clearly demonstrate that the option of physician-assisted dying has not been unwillingly forced upon those who are poor, uneducated, uninsured or otherwise disadvantaged.<sup>29</sup> The Reports show the following:

- use of physician-assisted dying is strongly associated with a higher level of education; those with a baccalaureate degree or higher were 7.6 times more likely than those without a high school diploma to choose physician-assisted dying.<sup>30</sup>
- ninety-nine percent of patients opting for physician-assisted dying during the DIGNITY ACT's first six years had some form of health insurance and eighty-six percent were enrolled in hospice care.<sup>31</sup>
- use of physician-assisted dying is limited. During the first six years in which physician-assisted dying was a legal option, a total of only 171 Oregonians chose it.<sup>32</sup> The number of terminally ill adults choosing this option in 2003 represented only one-seventh

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<sup>28</sup> See, e.g., Amy D. Sullivan et al., *Legalized Physician-Assisted Suicide in Oregon, The Second Year*, 342 *New Eng. J. Med.* 598 (2000); Arthur E. Chin et al., *Legalized Physician-Assisted Suicide in Oregon, The First Year's Experience*, 340 *New Eng. J. Med.* 577 (1988). See also Quill/Cassell article re neutrality, reviewing Oregon experience with DIGNITY ACT, *supra* n.2.

<sup>29</sup> See, e.g., First Annual Report at 7 ("Patients who chose physician-assisted suicide were *not* disproportionately poor (as measured by Medicaid status), less educated, lacking in insurance coverage, or lacking in access to hospice care.").

<sup>30</sup> See Sixth Annual Report.

<sup>31</sup> *Id.* at 23.

<sup>32</sup> *Id.* at 19.

of one percent—i.e., 0.0014 percent—of Oregonians who died that year.<sup>33</sup>

Indeed, rather than posing a risk to patients or the medical profession, the DIGNITY ACT has galvanized significant improvements in the care of the dying in Oregon. These include:

- greatly increased enrollment by Oregon physicians in Continuing Education courses to improve their knowledge of the use of pain medications for the terminally ill, improving their ability to recognize depression and other psychiatric disorders, and more frequently referring their patients to hospice programs.<sup>34</sup>

In sum, the available data demonstrate that making the option of assisted dying available, far from posing any hazard to patients or the practice of medicine, has galvanized improvements in end of life care, benefiting all terminally ill Oregonians.

The experience in Oregon reveals much about *why* dying patients choose to hasten impending death. In nearly all cases, multiple concerns contributed to the request. The patient's most frequently cited concerns include a

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<sup>33</sup> *Id.* at 5.

<sup>34</sup> *Id.*; see also Quill, Ganzini, Tolle articles, cited *supra* n.2; see also, Lawrence J. Schneiderman, MD, Book Review, JAMA 1/26/05, vol. 293, no. 4, p. 501, “*Physician-Assisted Dying: The Case for Palliative Care and Patient Choice* (eds. T. Quill, M. Battin, Johns Hopkins University Press 2004) (“Indeed, one of the unexpected yet undeniable consequences of Oregon’s Death with Dignity Act permitting physician aid in dying is that ‘many important and measurable improvements in end-of-life care’ occurred following the Act’s implementation. Rather than becoming the brutal abattoir for hapless patients that some critics predicted, the state is a leader in providing excellent and compassionate palliative care.”)

decreasing ability to participate in activities that made life enjoyable, the loss of autonomy, and the loss of dignity.<sup>35</sup>

A core argument made in opposition to legalizing the option of assisted dying contends that what terminally ill patients really need is good pain management and palliative care, not hastened death.<sup>36</sup> These opponents contend that motivation to improve pain management will be undermined if

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<sup>35</sup> SEVENTH ANNUAL REPORT, at 15. Detailed personal expressions of why some terminally ill Oregonians desire the option made legal by the Oregon law are contained in declarations filed with the court in *Oregon v. Ashcroft*. See, e.g., Supplemental Memorandum for Movant, *Oregon v. Ashcroft*, 192 F. Supp. 1077 (D. Or 2002) (No. CV 01-1647-JO). See also, Robert Pearlman & Helen E. Starks, *Why Do People Seek Physician-Assisted Death?*, PHYSICIAN-ASSISTED DYING, THE CASE FOR PALLIATIVE CARE & PATIENT CHOICE, 91, 93 (Timothy E. Quill & Margaret P. Battin, eds., Johns Hopkins Univ. Press 2004) (reporting on findings from interviewing 35 families where terminally ill patient desired to hasten impending death: “Our analysis identified 9 common factors. No single factor on its own ever accounted for a serious interest in a hastened death. Rather, interest usually arose out of an interactive process involving multiple factors in three broad categories: illness-related experiences (symptoms, functional losses, effects of pain medication, and the like), threats to the person’s sense of self (as revealed by his or her desire for control over the circumstances of dying and long-standing beliefs in favor of hastened death), and fears about the future.”); COMPASSION IN DYING: STORIES OF DIGNITY AND CHOICE, (Barbara Coombs Lee ed., NewSage Press 2003).

<sup>36</sup> See, e.g., NEW YORK STATE DEPARTMENT OF HEALTH, TASK FORCE REPORT ON LIFE AND THE LAW, WHEN DEATH IS SOUGHT: ASSISTED SUICIDE AND EUTHANASIA IN THE MEDICAL CONTEXT (1994) at <http://www.health.state.ny.us/nysdoh/provider/death.htm> (last visited June 12, 2005) (opposing legalization of assisted suicide and focusing on lack of adequate pain and symptom management at the end of life). This Report was quoted by the Court in *Washington v. Glucksberg*, 521 U.S. 702, 719 (1997). See generally, Kathleen Foley & Herbert Hendin, *The Case Against Assisted Suicide, For the Right to End-of-Life Care*, 331 (2002) (arguing if end-of-life care can be improved “assisted suicide will cease to seem an option that is truly needed”). See also Brief Amici Curiae of the American Medical Association, et al. at 6-8, *Vacco v. Quill*, 518 U.S. 1055 (1996) (No. 95-1858).

assisted dying is an available option.<sup>37</sup> Yet, as noted above, the Oregon experience has shown that legalization of assisted dying has galvanized efforts to *improve* pain management, and hospice enrollment in Oregon is stunningly high among patients who choose to make use of THE DIGNITY ACT.

Terminally ill Oregonians do not choose assisted dying because they have untreated pain, quite the contrary; Oregonians have access to good pain and symptom management. Only the relatively few patients who find that the cumulative burden of their terminal illness is intolerable, and who persist in a desire to hasten impending death, go on to utilize THE DIGNITY ACT.<sup>38</sup>

### III. OVERVIEW OF SUPPORT FOR THE OPTION OF PHYSICIAN AID IN DYING

Though Oregon is the only state to have yet legalized the option of physician aid in dying, support for the option is widespread nationwide.

- Harris poll, January 2002, found that sixty-five percent of respondents support legalization of the right to physician-assisted dying and sixty-one percent favored implementation of a version of the DIGNITY ACT in their own state.<sup>39</sup>
- Another group of studies found that between sixty-three and ninety percent of people with a terminal illness support a right to physician-assisted dying and would like to have the option available to them.<sup>40</sup>

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<sup>37</sup> See generally Brief Amici Curiae for the National Hospice Organization in Support of Petitioners, *Vacco v. Quill*, 518 U.S. 1055 (1996) (No. 95-1858 & No. 96-110).

<sup>38</sup> See, e.g., SEVENTH ANNUAL REPORT, at 15.

<sup>39</sup> Humphrey Taylor, *The Harris Poll #2, 2-to-1 Majorities Continue to Support Rights to Both Euthanasia and Doctor-Assisted Suicide*, Jan. 9, 2002, available at [http://www.harrisinteractive.com/harris\\_poll/index.asp?PID=278](http://www.harrisinteractive.com/harris_poll/index.asp?PID=278).

<sup>40</sup> Andrew Batavia, *The Relevance of Data on Physicians and Disability on the Right to Assisted Suicide: Can Empirical Studies Resolve the Issue*, 6 Psychol. Pub. Pol'y L., at 552-53 (citing W. Breitbart et al., *Interest in Physician-Assisted Suicide*



- In California, surveys in March 2006 and March 2005 found that 70% of California residents support the idea that "incurably ill patients have the right to ask for and get life-ending medication."<sup>41</sup> An assisted dying measure introduced in the California State Legislature in 2005 has garnered strong support.<sup>42</sup>
- Support is found among persons of diverse religious faiths.<sup>43</sup>

Support is also strong among physicians:

- A national survey conducted in March 2005 found that 57% of physicians believe it is ethical for a physician to assist a competent, dying patient hasten death.<sup>44</sup>
- A 2001 survey published by the *Journal of the American Medical Association* found that fifty-one percent of responding physicians

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*Among Ambulatory HIV Infected Patients*, 153 *Am. J. Psychiatry*, 238-42 (1996), B. Tindall et al., *Attitudes to Euthanasia and Assisted Suicide in a Group of Homosexual Men with Advanced HIV Disease*, 6 *J. of Acquired Immune Deficiency Syndrome* 1069 (1993)).

<sup>41</sup> Field Poll, reported AP/Fresno Bee, 3/2/05; Field Poll released 3/15/06, [www.field.com/fieldpollonline](http://www.field.com/fieldpollonline).

<sup>42</sup> The California Compassionate Choices Act. AB 651. See [www.CompassionateChoices.org/](http://www.CompassionateChoices.org/)

<sup>43</sup> In an amicus brief filed in *OR et al v Gonzales*, amici religious coalition advised the Court: "Numerous faiths, religious organizations, and religious leaders strongly support physician-assisted dying as an entirely legitimate and moral choice by which the terminally ill can hasten their impending deaths with dignity and integrity." 2005 WL 1687166 at p. 7. "Terminally ill patients' interests in religious and spiritual freedom thus dictate that they be allowed to make this choice according to their own beliefs, unfettered by the religious beliefs of others." 2005 WL 1687166 at p. 5. Amici Curiae Brief of 52 RELIGIOUS AND RELIGIOUS FREEDOM ORGANIZATIONS AND LEADERS IN SUPPORT OF RESPONDENTS, 2005 WL 1687166.

<sup>44</sup> Louis Finkelstein Institute for Social and Religious Research, poll conducted last week of February 2005 of 1,000 physicians. Reuters, Business Wire, March 3, 2005.

in Oregon supported the DIGNITY ACT and legalization of physician-assisted dying.<sup>45</sup>

- A nationwide survey published in 2001 in the *Journal of General Internal Medicine* found that forty-five percent of responding physicians believed that physician-assisted suicide should be legal, whereas only thirty-four percent expressed views to the contrary.<sup>46</sup>
- Mental health professionals recognize that dying patients can choose aid in dying and be fully mentally competent.<sup>47</sup>
- A significant number of medical associations have decided to embrace a position of “studied neutrality” on the question of

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<sup>45</sup> Linda Ganzini, MD, et al., *Oregon Physicians' Attitudes About and Experiences with End-of-Life Care Since Passage of the Oregon Death with Dignity Act*, 285 JAMA 2363, 2365 (May 9, 2001).

<sup>46</sup> Simon N. Whitney, MD, JD, et al., *Views of United States Physicians and Members of American Medical Association House of Delegates on Physician-assisted Suicide*, 16 J. Gen. Internal Med. 290, 292-93 (2001).

Another nationwide survey, published in the *New England Journal of Medicine* in 1998, focused on doctors who practiced in one of the ten medical specialties identified as likely to encounter dying patients (e.g., cardiology, geriatrics, neurology). Of those physicians responding, thirty-six percent said that, if it were legal to do so, they would be willing to hasten death by medication, and twenty-four percent stated that they would be willing to do so by injection. Meier, Emmons et al., *A National Survey of Physician-Assisted Suicide and Euthanasia in the United States*, 338 New Eng. J. Med. 1193 (Apr. 23, 1998).

<sup>47</sup> "End of life decisions by terminally ill patients are not akin to what is commonly termed 'suicide', which is considered to be a self destructive act often related to feelings of depression. These decisions to hasten death are more accurately paralleled to a patient's thoughtful decision to decline life sustaining measures: a product of judgment and reason, based on the desire to maintain one's dignity in a period where death is pending. A working group of the American Psychological Association stated that: "It is important to remember that the reasoning on which a terminally ill person (whose judgments are not impaired by mental disorders) bases a decision to end his or her life is fundamentally different from the reasoning a clinically depressed person uses to justify suicide." " Brief of Amicus Curiae Coalition of Mental Health Professionals in Support of Respondents, Oregon et al v Gonzales, 2005 WL 1749170 at p. 17.

legalizing physician-assisted dying, recognizing the division within the medical community on the question.<sup>48</sup>

#### IV. THE BACK ALLEY, COVERT PRACTICE

Although legal only in Oregon, physicians throughout the country regularly receive requests for assistance in dying. Nearly thirty-percent of physicians responding to a 1998 *New England Journal of Medicine* survey stated that, since entering practice, they had received a request from patients to hasten death.<sup>49</sup> Of those physicians who had received such a request, twenty percent had complied.<sup>50</sup>

A survey of physicians in Washington revealed that twelve percent of had received a request to hasten death during the previous year, and twenty-four percent of the patients who requested medications to hasten death received them, notwithstanding the fact that Washington does not have a law in place like the DIGNITY ACT.<sup>51</sup>

Patients who cannot find a physician willing to assist under existing law often act alone or with assistance from family members. Many people shared such stories in amicus briefs submitted to the Supreme Court in the *Glucksberg, Quill* and *OR v. Gonzales* cases. These stories detailed the suffering of loved ones who did not have access or authority to end their own

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<sup>48</sup> Timothy E. Quill, M.D., and Christine K. Cassel, M.D., *Professional Organizations' Position Statements on Physician-Assisted Suicide: A Case for Studied Neutrality*, *Annals of Internal Medicine*, vol. 138(3), pp. 208-11 (Feb. 2003).

<sup>49</sup> Meier, Emmons *et al.*, *A National Survey of Physician-Assisted Suicide and Euthanasia in the United States*, 338 *New Eng. J. Med.* 1193 (Apr. 23, 1998).

<sup>50</sup> *Id.*

lives. One woman told the story of her husband who had terminal cancer of the spine, lungs, and lymphatic system. Unwilling to await death in a drugged state, her husband kissed his wife good-bye and shot himself in the front yard. "I wish I could have been with him at the end, but he said 'no, it will be messy.'"

Another woman detailed the death of her daughter who was dying of bone cancer. Despite the excruciating pain, her daughter feared for her mother's participation in ending her life. "I should be able to talk with my doctor and plan this, not ask my mom. Mom, what if you go to prison? What will happen to you?" Nonetheless, the woman assisted her daughter by giving her medication. "It was the ultimate act of love a mother could do for her suffering, dying child." When her daughter died, the woman was finally able to hug her daughter without hurting her.<sup>52</sup> Many other such stories have been told: from loved-ones who helped patients die, to others who helplessly watched patients die and the resulting effects on the surviving family members.

Thus, the question is not whether assisted dying will occur, but rather whether it will occur in a regulated and controlled fashion with safeguards and scrutiny, or whether it will occur covertly, in a random, dangerous and unregulated manner.

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<sup>51</sup> Back, Wallace et al., *Physician-Assisted Suicide and Euthanasia in Washington State*, 275 JAMA 919 (Mar. 27, 1996).

<sup>52</sup> See Brief Amicus Curiae Surviving Family Members, *Oregon v. Gonzales*, 2005 WL 1749164.

**V. CONCLUSION**

In *Glucksberg* and *Quill* the Supreme Court recognized that Justice Brandeis's concept of the states as laboratories was particularly applicable to physician assisted dying. The Court's conclusion in those cases that the federal constitution does not bar states from prohibiting physician assisted suicide rested in large part on a reluctance to reach a premature constitutional judgment that would cut off the process of democratic decision making in the states.

It is timely, prudent and humane for states to enact laws to empower terminally ill, mentally-competent adult citizens to control the timing and manner of their deaths by enabling them to obtain medications from their physician that could be self-administered to bring about a peaceful and humane death, subject to careful procedures.<sup>53</sup> Passage of such laws would harm no one, and would benefit both the relatively few patients in extremis who would make use of them, and a great many more who would draw comfort from knowing this option is available should their dying process become intolerable to them.

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<sup>53</sup> As the Supreme Court noted this Term: "Oregon's regime is an example of the state regulation of medical practice that the CSA presupposes." *Gonzales v. Oregon*, 126 S.Ct. 904, U.S., 2006, p. 923.

**Testimony of U.S. Senator Ron Wyden  
Before the Senate Committee on the Judiciary  
Subcommittee on the Constitution, Civil Rights and Property Rights  
May 25, 2006**

Mr. Chairman, when Oregonians first adopted the Death With Dignity Act and then defended it on a second ballot initiative, they sent their government a clear message. When the American people resisted government interference in the tragic case of Terri Schiavo, they sent their government a clear message. That message is that death is an intensely personal and private moment, and in those moments, the government ought to leave well enough alone. The government ought not to attempt to override or preempt the individual's and the family's values, religious beliefs, or wishes.

I have testified before, and it bears repeating: I opposed physician aide in dying both as an Oregon voter and as a senator. As the former Director of the Oregon Gray Panthers I witnessed first hand how many poor and vulnerable individuals receive inadequate health care. I worried primarily about the adequacy of the Oregon ballot measures' safeguards to protect the poor elderly, and as a result, I voted against the Oregon ballot measure – not once, but twice as a private citizen.

Despite my personal objections, I firmly believe that my election certificate does not give me the authority or the right to substitute my personal and religious beliefs for judgments made twice by the people of Oregon. I will continue to strongly oppose any legislative or administrative effort to overturn or nullify the will of Oregon's voters on this matter.

Had Oregon acted hastily or without thorough examination and debate, I might not be in a position defend the Oregon law. No one can accuse Oregonians of acting precipitously in approving the measure: the voters of Oregon did so only after two lengthy and exhaustive debates that dominated water cooler and dinner table conversation for the better part of two years.

The issue of physician aid in dying is settled as far as my state of Oregon is concerned. My state has endured two legal ballot initiatives, court challenges to stop the implementation of the law, attempts in Congress to overturn the law, an attempt to overturn the law through administrative action by the Federal government, and, most recently, a challenge that went to the U.S. Supreme Court. Each time, the will of a majority of Oregonians prevailed.

During the eight years the law has been in effect, its opponents have combed through the law looking for possible pitfalls to exploit. However, the law still stands.

During the eight years the law has been in effect, its opponents have warned there would be abuses and a stampede to Oregon. The law has not been abused. In fact, over eight years, an average of about 30 Oregonians a year have used lethal prescriptions. This, of course, is a tiny fraction of Oregonians who faced terminal illness during that time.

While I do not know how I would vote were the issue to appear on the Oregon ballot once more, I believe it is time for me to acknowledge that my fears concerning the poor elderly were thankfully never realized, and the safeguards appear to have worked quite well in preventing potential abuses.

What is often not discussed by opponents of the Oregon law is the Oregon Death With Dignity Act has brought about many improvements in end of life care in Oregon. Pain management has improved. My state remains the only state to discipline a physician for the under-treatment of pain. However, perhaps the most important side effect of the law is that families, health professionals and patients know they can, and should have conversations about how they want to die and what their wishes are concerning treatment.

In 1997, the U.S. Supreme Court decided two important cases that should inform this discussion. The Court in *Washington v. Glucksberg* and *Vacco v. Quill* rejected any constitutional right of terminally ill patients to physician aid in dying, but, equally important, the Court in those decisions left the states free to permit or prohibit assistance in dying. Indeed, the high Court encouraged states to proceed with their various initiatives in this area. Oregon has done just that.

Historically and constitutionally, states have always possessed the clear authority to determine acceptable medical practice within their borders. States are responsible for regulating medical, pharmacy and nursing practice. Even the preamble to Medicare (42 USC 1395) states that "Nothing in this title shall be construed to authorize any Federal officer or employee to exercise any supervision or control over the practice of medicine or the manner in which medical services are provided..."

The scientific health literature is full of studies documenting how medical practice differs from region to region, state to state and sometimes from medical institution to medical institution. End of life care should be no different.

While other states have considered physician aid in dying since Oregon passed and implemented the Death With Dignity Act, they have not adopted it. That is their choice. Yet, no one challenged their decisions in court. Neither the Congress nor the Administration attempted to overturn their decisions. Oregon's decision, reached through legal means, should be respected as well. Fair-weather friends of States' rights should be reminded that States' rights does not mean just when you think the state is right.

Mr. Chairman, I truly believe there is real common ground and that the nation would benefit if we were to focus our efforts there. All of us would like to reduce the desire and demand for physician aid in dying. In order to do that, pain management needs a huge boost, not another set back.

Previous attempts to negate Oregon's law have damaged pain management in every corner of the United States. Even the New England Journal of Medicine editorialized against that attempt out of concern for the impact on pain management nationwide saying: "many doctors are concerned about the scrutiny they invite when they prescribe or administer controlled substance and they are hypersensitive to drug seeking behavior in patients. Patients as well as doctors often have exaggerated fears of addiction and the side effects of narcotics. Congress would make this bad situation worse."

Pain management is in a sorry state in this country. Senator Smith and I introduced the Conquering Pain Act to help provide families, patients and health professionals with assistance so that no patient would be left in excruciating pain waiting for the doctor's office to open up.

The Medicare hospice benefit, created in 1987, has not been revised significantly since then. I have legislation, the Medicare Hospice Demonstration Act, to test new ways of bringing hospice benefits to the patient. For example, Medicare currently requires terminally ill patients to choose between "curative" care and hospice. In plain English, that means you can't get hospice unless you give up hope. I contend that people do not get into hospice soon enough to get its full benefits if they're forced to make such a choice. My idea, which Aetna is currently testing, would set aside this "either or" choice, allowing hospice to begin while the patient continues with curative care.

The nation also has a shortage of providers – physicians and nurses --trained in palliative care. Legislation I authored, "The Palliative Care Training Act," provides funding to assure there is a medical faculty trained in palliative care for all ages.

It is a sad fact that not everyone can be cured. As the number of ways to prolong life multiplies, end of life care issues will be more controversial, more difficult and more painful. The aging of our population will bring more families face-to-face with these issues, as well. I contend that the more that is done to improve end of life care and to help support patient and family decisions, the less people will turn to physician aid in dying.

The country's legal system should not make those decisions more difficult, or more complicated.

For the citizens of Oregon, the Death With Dignity Act has brought about improvement in many areas and encouraged conversations that many would never have had otherwise. For many, it has brought a small measure of peace of mind, knowing that they can remain in control of their lives if they choose to do so.

In Oregon, the end of life process has been decriminalized. And although I could not prove it, I believe in Oregon we have fewer physician aid in dying cases than in other states where that kind of action is prohibited.

Mr. Chairman, let me close by saying that I know these are deeply personal issues for all Americans. My state has chosen a unique path. But rather than pursue a bitter and divisive debate over physician aid in dying, I would offer that we work together to make the end of life time a better one for all Americans.

