

American Medical Association

Physicians dedicated to the health of America



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FAX TRANSMISSION SHEET

Date: _____

To: Sarah Bianchi
Chris Jennings OK

From: Richard A. Deem
Vice President, Government Affairs
Tel: (202-789-7413)

Message:

Attached are materials that may fulfill your request.
I couldn't put my hands on record case that may be
what your after. Check LEXUS FOR Negron v Patel
U.S. Dist Ct Eastern Dist. of PA - 5/8/98 Doc No
97-4366. Case involves Salmonella poisoning - brain
damage, partial amputation of child's foot, some paralysis

Also see story on PBS Frontline Show ->
MD upset w/ child deformity cases

Total Pages (including cover sheet): 12

Reply Fax Number: (202)789-4692
Government Affairs

'The High Price of Health' Traces Managed Care's Rise

PBS Show Looks at Quality and Accountability

By SANDRA G. BOODMAN
Washington Post Staff Writer

There is a brief scene near the end of tonight's episode of "Frontline," the PBS television news show, that illustrates with searing clarity the extraordinary impact that the managed care revolution has had on the practice of medicine.

Ralph Holmes, chief of plastic surgery at the University of California, San Diego, specializes in painstakingly reconstructing the faces of children with rare birth defects. A decade ago, his presence on the staff of a large academic medical center like UCSD Medical Center would have been an asset.

That was before managed care swept into San Diego. These days Holmes finds that he has become a liability, not because he practices bad medicine but because his hospital loses money on every case he performs. Increasingly, managed care companies are eschewing UCSD Medical Center in favor of less expensive doctors and hospitals.

To keep his imperiled division afloat, Holmes has begun doing surgery that will bring in more money. Increasingly his days are filled with face lifts and liposuctions and other cosmetic procedures for which patients pay in full—and in cash.

This surgeon, who spent a dozen years perfecting techniques to rebuild badly deformed ears, listens politely while a deeply tanned thirtysomething woman in a midriff top tells him she wants the flab surgically vacuumed off her thighs.

The camera then cuts to a shot of Holmes, who was born with malformed ears, tenderly cradling the face of a frightened little girl before she is wheeled into the operating room. The juxtaposition of these images is unusually affecting and disturbing.

So is much of the rest of this hour-long program entitled "The High Price of Health," which airs at 9 p.m. on Channels 22 and 26. The program, produced by Rachel Dretzin, examines what has happened in the four years since the Clinton administration's health care plan failed.

In addition to the beleaguered surgery department at UCSD, Dretzin focuses on the struggles involving nurses at Beverly Hospital, a small community facility on Massachusetts' North Shore, and on Malik Hasan, one of the captains of the new industry of for-profit health maintenance organizations.

The segment involving Beverly Hospital, which is struggling to stay open by using more unlicensed personnel instead of registered nurses, is less compelling. While the nurses complain that they are overworked and that patient care is suffering, there is no good evidence that this is happening. And the implication that towns like Beverly should have a community hospital is dubious. It was furious overbuilding by hospitals

and the resulting surfeit of beds that in part led to the current health crisis.

Hasan, the founder and chief executive officer of Foundation Health Systems Inc., one of the nation's largest and fastest-growing health maintenance organizations (HMOs), provides a fascinating, if chilling, portrait of for-profit medicine.

Hasan, a Pakistani native who practiced as a neurologist in Colorado before founding an HMO, is described by Wall Street Journal managed care reporter George Anders as "brilliant, dead certain of his own virtue" and "unabashedly proud of how rich he is." In a remarkably short time he has built a company with \$8 billion in revenue that is still growing.

Hasan, whose imperious manner is evident before he castigates doctors and hospital officials for "hand-wringing and whining," is, he notes several times, deeply interested in "efficiency" and in pleasing Wall Street analysts.

Fortunately, Dretzin doesn't bemoan the good old pre-managed-care days, as many physicians are wont to do, when doctors could do pretty much what they wished. She notes that in the old days—of say 1988—there were no incentives to practice good medicine in a cost-effective manner. The more doctors and hospitals did, the more money they made. As Hasan notes, "there was hardly any accountability for what the physician did."

But as the program makes clear, there is hardly any accountability now for what managed care companies do. And the stated goal of managed care—to deliver quality care while controlling costs—has too often meant that quality takes second place to the bottom line.

As one UCSD surgeon says, "We no longer talk about patients. We talk about covered lives. We no longer talk about doctors. We talk about providers."

Viewers see a graphic example of the price some patients pay when the bottom line trumps quality. One teenage boy who needed a new ear was sent not to Holmes, but to a surgeon with far less experience—and skill. The horrifying result is a mound of misshapen flesh and cartilage that resembles a piece of cauliflower. After protests from the boy's family, the HMO agreed to send him to another surgeon, outside the plan, who redid the botched operation.

Such cases, Holmes notes, are becoming increasingly common. Some health plans are asking surgeons to make rubber ears for children that can be clipped onto a bone, in lieu of more expensive and exacting surgery. The tragedy, Holmes observes, is that this so scars the ear that these children can never have an ear remade out of normal tissue when they become adults.

The viewer is left wondering about the purpose of a revolution that ends up rewarding a surgeon for doing liposuction, but not for rebuilding a child's damaged face. ■

JOHN SHADEGG
4TH DISTRICT, ARIZONA

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Congress of the United States
House of Representatives
Washington, DC 20515-0304

March 10, 1998

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AND ENERGY AFFAIRS
NATIONAL SECURITY, INTERNATIONAL AFFAIRS,
AND CONSUMER INTERESTS

Robert F. Beauchamp, M.D.
Vice President and Medical Director
CIGNA Private Practice Plan of AZ
11001 North Black Canyon Highway
Suite 400
Phoenix, Arizona 85029-4754

Dear Dr. Beauchamp:

Thank you for writing to express your concerns regarding H.R. 1415, the Patient Access to Responsible Care Act of 1997 (PARCA). I appreciate the opportunity to respond and apologize for the delay in getting back to you. As your letter indicated, I do value the time I get to spend with my family; however, I am also very interested in hearing your viewpoint on this issue.

Health Maintenance Organizations (HMOs), as you know, are an emerging alternative to traditional fee-for-service health care in the United States. As with the emergence of all new fields in a market, problems and concerns arise. The market usually responds to correct such concerns. Nevertheless, we must remember that in the health care field peoples' lives are at stake.

I am hopeful that HMOs and managed care companies will voluntarily implement necessary consumer protections. I am concerned, however, that the Employee Retirement Income Security Act of 1974 (ERISA) may be causing millions of Americans to be denied proper health care and in some instances to be injured or killed without any meaningful legal recourse against those responsible.

As the tension between reducing costs and providing care continues, PARCA seeks to provide certain basic patient protections to ensure that Americans know what care they are entitled to under their plan and that they actually receive that care. Currently, this legislation is pending before the Commerce Committee's Subcommittee on Health and Environment. More importantly, the Speaker has appointed a health care task force to address problems in the managed care arena. That task force is trying to develop a compromise alternative to PARCA.

Historically, as you know, state legislatures and insurance commissioners have been responsible for protecting patients by enacting laws and regulations governing insurance

Robert F. Beauchamp, M.D.

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companies and health care plans. However, in 1974 when Congress passed ERISA, it blocked the traditional role that states play in providing protections for patients, specifically preempting state regulatory laws from governing ERISA plans. In addition, Congress also granted HMO's and managed care companies immunity from consequential damages for health insurance plans governed by ERISA, even where their negligence actually caused the injury.

As a result, health plans which are governed by ERISA under current law are both exempt from state patient protection laws and are immune from any consequential damages their negligence may cause. (See *Corcoran v. United Healthcare, Inc.*) According to some estimates, over 60 percent of the insured population is covered by an ERISA governed plan.

As a physician yourself, you are no doubt aware that the doctors who practice under these plans are not immune from suit for their actions. And, when health plans and their medical directors wrongfully or negligently delay or deny care, they should not be absolutely immune either. As you are also no doubt aware, in Arizona the Board of Medical Examiners (BOMEX) has asserted regulatory authority over decisions by HMO medical directors who make improper decisions in denying care. And, the Arizona Supreme Court has upheld the right of BOMEX to do so. (See *Murphy v. BOMEX*)

As a conservative who supports individual responsibility and accountability in business, medicine, and throughout our society and who teaches his children that there are consequences for their conduct, I simply do not believe that anyone should have total immunity from the consequences of their conduct.

ERISA was primarily written and intended to require greater accountability in the regulation of pension plans. Since that time, the emergence of HMOs as a cost-effective option for health care coverage has dramatically changed the health care climate in this nation.

A variety of patient protections, from information availability to access to care, that have been or are being addressed at the state level are not addressed by ERISA. These protections simply do not exist at the federal level for the ERISA-covered population. Consequently, for millions of people, ERISA is not sufficient to protect them from improper health care practices that wrongfully limit or deny needed and deserved care.

I believe the abuses which PARCA seeks to address have increased to the point where they can no longer be ignored. Literally hundreds of stories appear in the daily papers and news magazines across America detailing abusive practices by HMO's and managed care companies. I would be happy to provide you with an almost endless supply of such anecdotal information. (See *Washington Post* 3/11/98, patient injured in a 40 foot fall while hiking denied coverage for her \$10,000 hospital bill after being air-evaced to a hospital suffering a skull, arm and leg fracture. Coverage denied because she did not receive emergency room "pre-authorization!" What was she supposed to do, place a phone call from the helicopter?)

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I believe that these abuses are the result of the combination of an absence of state or meaningful federal regulation and the grant of total immunity for consequential damages. The managed care industry simply cannot have it both ways -- no regulation by the government and no oversight by the legal system.

The exemption from state regulation is an accommodation to large companies so that they can conduct business in different states without having to live under multiple state regulatory schemes. In this respect it makes some sense. However, I believe state regulation, not federal, would do a better job of protecting people and would be less burdensome on businesses as well. And, I do not believe the creation of a comprehensive federal regulatory scheme, and the necessary bureaucracy at the national level to enforce such regulations, is in the best interest of either patients or the health care industry.

On the other hand, the total exemption from liability for consequential damages provided by ERISA cannot be justified. Even if your company or other reputable and well-managed companies consistently act in the best interests of their patients and never deny or delay proper care, the absence of regulatory or judicial oversight would inevitably be exploited by others who are less scrupulous.

Contrary to the radio ads run against me, I do not favor intrusive federal regulation of the health care industry. I have, in fact, consistently and aggressively opposed excessive government regulation of the free market. Nor do I seek, as the radio ads asserted, to increase health care costs by excessive regulation thus resulting in damage to small businesses or increasing the number of uninsured people in our society.

In that regard, I recognize some of the drafting problems in PARCA. I will not vote for PARCA in its current form and have told Congressman Norwood so. But, not all of the criticism of PARCA is fair or well-founded.

I do not support and will not vote for any bill that includes "guaranteed issue," "community rating," or "any willing provider" provisions. It is worth noting, however, that Congressman Norwood opposes "guaranteed issue," "community rating," and "any willing provider" requirements. And, while he asserts that the bill does not mandate these as written, he is willing to rewrite the bill to make these points absolutely clear.

Since most of the alleged regulatory burden and the vast majority of the additional cost the bill's critics say it would cause arise out of these three points, their clarification should remove concern about them and go a long way toward addressing the regulatory burden and cost issues.

Beyond these issues, PARCA is intended to establish basic guidelines to protect patients in self-insured plans. Among other things, the bill seeks to:

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- ensure that patients can choose health professionals within their health plan;
- offer patients access to due process avenues of appeal;
- give patients information to make intelligent decisions about their health care;
- guarantee health plan responsibility for injuries suffered due to policies of the health plan;
- ensure that patients have access to providers to receive the benefits covered by the health plan in a timely manner, and
- guarantee open communication between patients and providers.

If you or your company oppose these goals or object to specific provisions in PARCA that I have not addressed, please advise me immediately.

Health care is one of the most sensitive issues Congress faces. To this end, I appreciate different perspectives as we continue to tackle the challenges of health care improvement in this country. Again, thank you for sharing your views. I look forward to hearing from you on this or any other issue of importance to you.

Sincerely,

John Shadegg
Member of Congress

JS:am

RICHARD J. DURBIN
ILLINOIS

United States Senate

WASHINGTON, DC 20510-1304

July 9, 1997

INCREASE PATIENT AND DOCTOR PROTECTIONS BY HOLDING HMOS ACCOUNTABLE FOR THEIR HEALTH CARE DIRECTIVES

Dear Colleague:

I am writing to urge you to cosponsor the Employee Health Insurance Accountability Act of 1997 (EHIAA). This bill would hold employer-sponsored health maintenance organizations (HMOs) accountable for patient injuries that result from their direction of a patient's medical care. Allow me to explain why this bill is so necessary with some real life examples:

Due to her history of high-risk pregnancies, Ms. Florence Corcoran's physician determined that she should be hospitalized during the waning weeks of her latest pregnancy. Her employer-sponsored HMO disagreed and only authorized 10 hours a day of home nursing care. While the nurse was off-duty, Ms. Corcoran's unborn child suffered distress and died. As ERISA is currently interpreted by the courts, Ms. Corcoran will never obtain proper redress for the death of her unborn child and her HMO will never be held accountable. She can only sue her doctor --not her employer-sponsored HMO --even though her doctor was not at fault.

Mr. Basile Pappas suffering from numbness in his arms and unable to walk sought treatment at a local community hospital at 11:00 a.m. The emergency room doctor made a difficult diagnosis and determined that Mr. Pappas had a cervical-epidural abscess, a condition that was compressing his spinal cord. The emergency room doctor correctly concluded that unless Mr. Pappas was treated immediately by a spinal cord trauma unit, he could suffer severe paralysis. At 12:30 p.m. the emergency room doctor made arrangements to transfer Mr. Pappas to a local university hospital which was the only hospital in the area that had such a trauma unit and that could assure Mr. Pappas' immediate admission. Mr. Pappas' employer-sponsored HMO, however, would not allow Mr. Pappas to be transferred to the university hospital because it was not part of his service plan. Even after the emergency room doctor explained to the employer-sponsored HMO the urgency of the situation, the HMO refused. The HMO's physician who denied the request refused to even speak to the emergency room doctor. The emergency room doctor expeditiously made other arrangements to transfer Mr. Pappas to a hospital with the appropriate facilities that could admit Mr. Pappas. Nonetheless, Mr. Pappas was not treated until 3:30 p.m. and now suffers from permanent quadriplegia resulting from compression of his spine by the abscess. A court determined that the employer-sponsored HMO was immune from liability due to ERISA, and the hospital and Mr. Pappas' physicians were left paying for Mr. Pappas' injuries although they had little to no culpability.

BACKGROUND:

Section 514(a) of ERISA preempts state lawsuits against the entities that provide employee benefits and retirement plans. This includes medical malpractice suits against an employer-sponsored HMO. Yet medical malpractice falls almost exclusively within the jurisdiction of the states. Employer-sponsored HMOs, consequently, are not held accountable for their treatment rules and coverage determinations.

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Ms. Corcoran and others like her cannot bring suit in state court where they should rightfully receive redress for their losses. Instead, they are forced to bring suit in federal court where they can only receive the cost of the denied medical benefit. In short, Ms. Corcoran's unborn child died needlessly, and the only penalty to the HMO is the few hundred dollars it would have cost to properly hospitalize her. As Newsweek observed, because "there's no financial penalty when [employer-sponsored] health plans are negligent, what's to stop these profit-driven creatures from delivering inadequate medical care?"

The other victims in these cases are the doctors who end up in court and are held liable for the actions of HMOs. To quote the Chicago Tribune, "[HMOs], which care for more than 60 million people, are telling courts across the country that they cannot be held responsible for medical malpractice in cases involving patients who receive care through an employer-sponsored health plan . . . HMOs are shifting virtually all of the risk of patient care to physicians, even though the HMOs can force doctors to change their clinical decisions."

WHAT EHIAA DOES:

How can we protect patients, avoid unnecessary lawsuits against doctors, and hold employer-sponsored HMOs accountable for their actions? The authors of ERISA clearly never intended it to remove all consumer protections and to be used as a tool by HMOs to shirk their responsibilities. As Justice Souter when addressing this issue said "Nothing in the language of [ERISA] or the context of its passage indicates that Congress chose to displace general health care regulation, which historically has been a matter of local concern". My bill, therefore, amends Section 514(b) of ERISA to clarify that state medical malpractice suits against an employer-sponsored HMO are not preempted by federal law:

- (1) The measure holds employer-sponsored health insurance plans accountable for the consequences of their treatment rules and coverage determinations. This will increase patient protection, and create a powerful incentive for employer-sponsored HMOs to provide necessary care.
- (2) The measure provides patients with legal redress when their employer-sponsored HMO's treatment rules and coverage determinations cause them harm. Victims like Ms. Corcoran will no longer be left without the opportunity to seek just reparations for their injuries.
- (3) The measure reduces the likelihood that doctors will be sued for coverage determinations beyond their control. They will no longer face lawsuits simply because this is the only option that the patient has.

I hope you will co-sponsor this important initiative. If you have any questions or would like to co-sponsor, please call Anne Marie Murphy (4-8464) or Joel Wiginton (4-4022) of my staff.

Sincerely,



Richard J. Durbin
United States Senator



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Holding Health Plans Accountable

HMOs think patients and doctors should bear full legal responsibility for decisions made by the HMO.

By Jane Bryant Quinn
Tuesday, September 9, 1997

NEW YORK -- What's the Rx for patients injured by a health plan's decision to deny them critical treatment they should have had?

Patients can and do sue their doctors for medical malpractice. But their health insurers are usually off the hook. In most states, it's all but impossible to bring malpractice charges against an employee plan.

The plan may have told your doctor that it won't cover a particular treatment because it's not "medically necessary." If the doctor accepts that decision, however, and it turns out to be wrong, only the doctor can generally be held at fault.

The injustice of this is becoming increasingly clear, both to legislatures and the courts. Around the country, a movement is stirring to hold health plans accountable for the decisions they make. In May, Texas passed the first state law allowing patients to bring malpractice claims against HMOs and other managed-care plans.

In June, Missouri achieved a similar result, by making it clear that HMOs practice medicine. This opens them to malpractice claims, Marla Rothouse, a policy specialist at the Health Policy Tracking Service in Washington, D.C., told my associate, Kate O'Brien Ahlers. Connecticut has also opened the door a crack.

Some 20 other states are considering similar laws. Proposals are on deck in New Jersey, under study in Rhode Island and Washington state, and moving through the tortuous legislative process in New York and California

(with no guarantee of results).

There are even two proposals at the federal level. Rep. Charlie Norwood, R-Ga., wants to allow state malpractice actions, if a health plan makes a medical decision that leads to injury or death. Rep. Pete Stark, D-Calif., would create a federal malpractice law, available to injured patients in any state.

Federal appeals courts have also taken up the issue. Thanks to patient-friendly decisions, you can now sue in nine states: Delaware, New Jersey, Pennsylvania, Colorado, Kansas, New Mexico, Oklahoma, Utah and Washington.

In a few other states, malpractice cases have occasionally been allowed. A majority of states, however, still bar them completely. What insulates health plans from responsibility for their decisions? A federal law known as ERISA -- the Employer Retirement Security Act of 1974. This law was originally written to protect the integrity of pension plans. But its wording covers all company benefits, including health insurance.

Under ERISA, claims against company health plans have to be brought in federal court. But malpractice is a state offense. If you sue in the state and your case is moved to federal court, your malpractice claim no longer exists, no matter how careless the health plan was.

ERISA covers only employer plans. You can sue for malpractice in state court if you buy your own, individual plan.

Very few employer plans can be sued even under current law. Who are the lucky employees? Members of Congress, naturally, who always look out for Number One. Also state-government employees.

The managed-care plans whine that malpractice shouldn't apply to them because they don't make medical decisions. If they rule that a treatment isn't "medically necessary," they claim it's merely paperwork.

For a flavor of these arguments, you have only to turn to the hearings held in Texas. By all accounts, many of the legislators couldn't believe their ears. For example:

-- An HMO attorney was asked whether the plan should be

liable, if a woman in pain, who previously had cancer, isn't referred to a cancer specialist and dies of the disease. Said the attorney, no way. It's the patient's own fault. "The refusal to pay did not lead to that woman's death. She led to her death if ... her going to a doctor would have saved her." It was her obligation to find an oncologist who would take her uninsured.

-- Another HMO attorney testified that it was the doctor's fault if a patient wasn't treated after an HMO refused to pay. The "doctor could do (the procedure) without charge," he said.

-- An insurance attorney testified about a business plan he'd seen at a particular HMO, projecting the savings from cutting back on hospital referrals. The insurer figured that the change would increase its litigation costs by a few hundred thousand dollars, but the trade-off was worth it.

It's regrettable that lawsuits seem to be necessary. Florida Gov. Lawton Chiles vetoed a bill that would have allowed malpractice claims, arguing that lawsuits drive up medical costs. Consumers themselves don't want death claims, they want timely treatment.

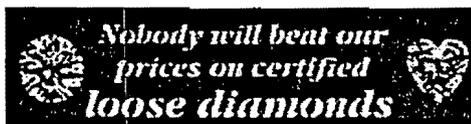
But the HMOs and other managed-care plans are bringing this backlash on themselves. When appeals are slow and there's no independent source of justice, where else can consumers turn?

Jane Bryant Quinn welcomes letters on money issues and problems but cannot offer individual financial advice.

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THE
CATHOLIC HEALTH
ASSOCIATION
OF THE UNITED STATES



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February 6, 1998

President William J. Clinton
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of more than 1,200 Catholic-sponsored facilities and organizations nationwide that make up the membership of the Catholic Health Association of the United States (CHA), I write with regard to the critical issues surrounding the protection of life and the provision of pain relief for those nearing the end of life.

I am writing specifically to urge you to: 1) support the Drug Enforcement Agency's (DEA) recent legal interpretation of the Controlled Substances Act regarding physician-assisted suicide; 2) encourage you to issue enforcement guidelines to the DEA urging it to be sensitive to the legitimate concern that overly aggressive or misguided enforcement could have a chilling effect on pain relief for persons at the end of life; and 3) appoint a task force to make concrete recommendations on how to reduce legal and regulatory barriers to *appropriate* pain relief for dying persons.

First, CHA strongly supports DEA's declaration that "delivering, dispensing or prescribing a controlled substance with the intent of assisting a suicide would not be under any current definition a legitimate medical purpose." The religious beliefs and values upon which both CHA and its member hospitals and long-term care facilities are founded compel us to reject assisted suicide. More generally, this practice is radically inconsistent with proper regard for the dignity of human life and irreconcilably incompatible with the appropriate ends of medicine.

The DEA's legal interpretation is completely consistent with your support for the Assisted Suicide Funding Restriction Act passed last year. In that legislation, you supported the proposition that no federal funds, programs, or health facilities should be used to further assisted suicide. Thus, from the federal government's perspective, assisting in a suicide is not a legitimate medical practice. Consistency demands that you support the legal interpretation provided by the administrator of the DEA.

Second, your support for a consistent legal interpretation does not mean that you cannot take ameliorative steps with regard to enforcement. CHA is acutely aware that the DEA's correct, legal interpretation, if not carefully implemented, may *unintentionally* have a chilling effect on physicians who prescribe, dispense, and administer appropriate and effective amounts of

Elena / Hore

Important, interesting info.
I suggest we work with
these guys whatever we do.
Their counsel, Peter Leibold, is
a good friend of mine. John

morphine and other opioids in treating pain as death approaches. Certainly, a physician would have reason for serious concern if the DEA routinely second-guesses his or her dosages to a dying person to determine if they violate the Controlled Substances Act. In a recent study, the Institute of Medicine (IOM) found that physicians have significant apprehension about legal sanctions related to addiction and anti-addiction regulations.

Therefore, when announcing your support for DEA's interpretation, CHA urges you to issue an enforcement directive to the agency concerning your expectations with regard to its agents' enforcement of the law. Specifically, the DEA must be aware of, and sensitive to, the impact that its investigation may have on the dispensing of needed pain relief medication to dying persons. The DEA should be aware that it is *not* a violation of the Controlled Substances Act to dispense controlled substances for the legitimate medical purpose of relieving pain, even if they may indirectly shorten the person's life. This essential distinction is codified in the Assisted Suicide Funding Restriction Act itself and was affirmed by the U.S. Supreme Court when it upheld laws prohibiting assisted suicide last June.

The DEA should initiate investigations or enforcement actions only when their agents have credible and substantive allegations that health care providers have established a pattern or practice of prescribing or dispensing controlled substances to persons for the purpose of helping them to take their lives. It is not, nor should it be, a DEA priority to expend significant resources second-guessing the opinions of health care providers about the controlled substances needed to adequately and appropriately relieve the pain of dying persons.

Third, CHA asks that you form a federal/state advisory task force to make concrete recommendations to you and to the 50 governors on how to reduce legislative and regulatory barriers to pain relief. A 1997 Institute of Medicine Study, *Approaching Death: Improving Care at the End of Life*, states the concern succinctly:

Outdated and scientifically flawed drug-prescribing laws, regulations, and interpretations by state medical boards continue to frustrate and intimidate physicians who wish to relieve their patient's pain. Addiction to opioids appropriately prescribed to relieve pain and other symptoms is virtually non-existent, whereas underuse of these medications is a well-documented problem (pp 5&6).

Specifically, the IOM identifies, among others, triplicate prescription laws, limits on the number of medication dosages that may be prescribed at one time, medical board policies, and state anti-addiction laws as barriers to effective pain relief.

President William J. Clinton

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CHA recognizes the critical need to address illegal drug use and diversion. Yet, as the IOM points out, there is little evidence that the prescription of opioids in the care of dying persons contributes in any meaningful way to illegal drug use and drug diversion problems. It is both counterintuitive and counterproductive if drug control laws tragically result in the increasing reluctance of physicians and other health professionals to treat dying persons by seeking to alleviate their pain. Dying persons should not be held hostage by regulations that, while rightly motivated, can cause great suffering and distress for them and their families.

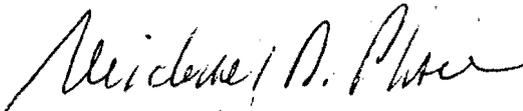
CHA and its member facilities and organizations are committed to provide dying persons and their families both competent and compassionate care. Toward that end several Catholic health systems and CHA have joined together in a collaborative effort, *Supportive Care of the Dying: A Coalition for Compassionate Care*. One specific goal of this project is to ensure that adequate and effective pain management is available to every person living with life-threatening illness so that they may live well even while dying.

Mr. President, concrete recommendations for reform by a federal/state task force on these issues will allow you to suggest legitimate steps to improve pain relief for dying persons. In this way, you can continue your consistent support for the principle that assisting in a suicide is not a legitimate medical purpose and, at the same time, suggest appropriate and necessary public policy mechanisms to improve pain relief for dying persons.

In conclusion, CHA urges you to remain consistent on the federal government's treatment of assisted suicide while exploring all available and legitimate methods for improving pain relief for those in the last stages of life.

With personal best wishes, I am

Sincerely,



Rev. Michael D. Place, STD
President

cc: Attorney General Janet Reno

- Hyde is soon going to introduce legislation to overturn AG possible interpretation, which may overturn DEA interpretation.

- DEA interpretation ~~is not~~ of law may be accurate, but we need very careful ~~to~~ implementation.

= Oregon may use indirect Medicaid dollars.

= Issues Federal license to dispense controlled substances.

= If intent is to aid suicide

= Doctors aren't proceeding enough now

= Possible task force to determine impropriety of state, Fed law

A&E Test tube baby



In Peter Weir's brilliant media satire, Jim Carrey's life is a television show



ERIC CLAPTON:
Guitar god or fallen?

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Friday,
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The Oregonian

THE LARGEST NEWSPAPER IN THE PACIFIC NORTHWEST

Suicide law passes U.S. re

GOV OFFICE RM187

■ The federal Controlled Substances Act doesn't bar the lethal prescriptions that Oregon permits, the Justice Department concludes

By **JIM BARNETT**
and **DAVE HOGAN**
of *The Oregonian* staff

WASHINGTON — U.S. Attorney General Janet Reno will announce as early as today that federal law

does not prohibit physician-assisted suicide in Oregon — ending seven months of legal limbo for terminally ill patients and their doctors.

Reno will unveil the essence of a U.S. Justice Department opinion stating that the federal Controlled

Substances Act does not forbid doctors from prescribing lethal doses of medicine, sources in Washington, D.C., told *The Oregonian*.

The long wait for the Justice Department opinion has not stopped the assisted-suicide law from being used. At least three terminally ill Oregonians have died with legally prescribed lethal medication since the law was reaffirmed in November.

But the announcement will remove a legal cloud that has deterred some doctors and health care organizations in Oregon from allowing patients to end their lives if they are expected to live less than six months. At a November meeting of the Oregon Medical Association's governing body, physicians expressed concern about the implied threat that if they participated in an assisted suicide, they could lose their

ability to prescribe controlled substances.

Lack of clarity from the Justice Department also spread a chill over some policy-makers. A joint state-federal law, postponed taking its next steps until it hears Reno's opinion.

The Justice Department announcement is likely to touch off heated debate on Capitol Hill, where some members of Congress are e

Bombing

ACADEMIC ALL-STARS

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Suicide: Congress, lobbyists ready to wade into the fray

Continued from Page One
in Washington, D.C., after the first reports of an assisted suicide surfaced in March.

The news sent a shock wave through Congress, prompting dozens of members to write to Reno. Most urged her to accept an interpretation of the Controlled Substances Act that would disqualify assisted suicide as a "legitimate medical purpose" of drugs.

That interpretation was first advanced by Thomas Constantine, a Reno deputy who heads the U.S. Drug Enforcement Administration, in a written reply to Rep. Henry Hyde, R-Ill., chairman of the House Judiciary Committee.

Constantine sent his letter on Nov. 5, 1997, without consulting Reno. Reno has not publicly chided Constantine, a career law enforcement officer, but responded by calling for an internal review of his opinion.

In January, Sen. Ron Wyden, D-Ore., confirmed that the review team, headed by counselor Jonathan D. Schwartz, found that the Controlled Substances Act could not be interpreted to prevent doctors' participation in patients' suicides.

Reno's announcement is expected to focus on the narrow legal question at hand. Sources said it is possible but unclear whether the Clinton administration will address the issue further.

The issue of assisted suicide has been brought to the attention of numerous White House advisers. Those advisers would support Reno's position but could offer other initiatives.

If the administration does not act, Congress seems eager to take up the issue in its next session, if not in the few remaining workdays before fall elections.

“
Encouraged legislators to contact the Justice Department and Food and Drug Administration in order to make the use of drugs for assisted suicide illegal and outside the practice of medicine.

1997 National Right to Life Committee report

”

Opponents of assisted suicide include key Republicans such as House Speaker Newt Gingrich of Georgia and Utah Sen. Orrin Hatch, chairman of the Senate Judiciary Committee, as well as Hyde.

Northwest Republicans who have signed letters to Reno include Rep. Bob Smith of Oregon and Reps. Jennifer Dunn, George Nethercutt and Linda Smith of Washington.

Oregon Democrats, including Wyden, have urged Reno to steer clear of the assisted-suicide law. A number of national surveys show broad public support for a terminally ill patient's right to choose assisted suicide, and Oregon voted twice in favor of the law.

But congressional opposition to assisted suicide spans the political spectrum. Among more than 190 members who have written to Reno

are 36 Democrats, including Sen. Joseph Biden of Delaware and Rep. James L. Oberstar of Minnesota.

One Republican aide said recently that making the practice illegal would be as simple as passing a one-page bill specifying that it is not a legitimate medical use. President Clinton has said he opposes assisted suicide.

Already, interest groups are gearing up for a fight.

On May 4, the Bass and Howes Inc. lobbying firm registered in Washington, D.C., to represent the Oregon Death With Dignity Legal Defense & Education Center. And in its 1997 lobby report, the National Right to Life Committee noted that it had begun contacting members.

"Encouraged legislators to contact the Justice Department and Food and Drug Administration in order to make the use of drugs for assisted suicide illegal and outside the practice of medicine," the report said.

Other groups also have asked Congress to oppose assisted suicide, including the National Council of Catholic Bishops.

Perhaps anticipating a renewed wave of interest in the issue, Reno declined to say Thursday when she would announce results of the legal review. She said only that she hoped to announce her decision this month.

Erin Hoover of The Oregonian staff contributed to this report.

Jim Barnett and Dave Hogan are members of the Washington, D.C., bureau of The Oregonian, 1101 Connecticut Ave NW, Suite 300, Washington, D.C. 20036. Barnett also may be reached at 202-383-7819 and Hogan at 202-383-7814.

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FEDERATION



Office of the Attorney General

Washington, D. C. 20530

June 5, 1998

The Honorable Orrin G. Hatch
Chairman
Committee on the Judiciary
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

This is in response to your request concerning the question whether the Department of Justice, through the Drug Enforcement Administration ("DEA"), may invoke the Controlled Substances Act ("CSA"), 21 U.S.C. §§ 801-971, to take adverse action against physicians who assist patients in ending their lives by prescribing controlled substances. The issue has arisen in the context of Oregon's "Death with Dignity Act," Oreg. Rev. Stat. §§ 127.800-127.995, which permits physicians to assist competent, terminally ill patients in ending their lives in compliance with certain detailed procedures. The Department has reviewed the issue thoroughly 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.

The Oregon Act was approved by Oregon voters on November 8, 1994, and went into effect on October 27, 1997. The Act provides for a detailed procedure by which a mentally competent, terminally ill patient may request to end his or her life "in a humane and dignified manner." O.R.S. § 127.805. The procedure requires, for example, that the patient's competence and the voluntariness of the request be documented in writing and confirmed by two witnesses, see id. § 127.810(1), that the patient's illness and competence and the voluntariness of the request be confirmed by a second physician, see id. § 127.820, and that the physician and patient observe certain waiting periods, see id. §§ 127.840, 127.850. Once a request has been properly documented and the requisite waiting periods have expired, the patient's attending physician may prescribe, but not administer, medication to enable the patient to take his or her own life. As a matter of state law, physicians acting in accordance with the Oregon Act are immune from liability as well as any adverse disciplinary action for having rendered such assistance.

The Honorable Orrin G. Hatch
Page 2

Prior to the Oregon Act's taking effect last year, you wrote to DEA Administrator Thomas Constantine seeking the DEA's view as to whether delivering, distributing, dispensing, prescribing, or administering a controlled substance with the intent of assisting in a suicide would violate the CSA notwithstanding a state law such as the Oregon Act. In response, Administrator Constantine explained that "physician-assisted suicide would be a new and different application of the CSA," and that the determination whether to pursue adverse action under the CSA would first require "a medico-legal investigation" involving "state and local law enforcement agencies and prosecutors." He also stated, however, that "the activities that you described in your letter to us would be, in our opinion, a violation of the CSA." Subsequently, many other Members of Congress have sent letters urging that I support the DEA's conclusions and enforce federal laws and regulations accordingly. I have received other correspondence supporting a contrary conclusion.

The Department has conducted a thorough and careful review of the issue of whether the CSA authorizes adverse action against a physician who prescribes a controlled substance to assist in a suicide in compliance with Oregon law.

The CSA is a complex regulatory scheme that controls the authorized distribution of scheduled drugs. Physicians, for example, are authorized to prescribe and distribute scheduled drugs only pursuant to their registration with the DEA, and the unauthorized distribution of drugs is generally subject to criminal and administrative action. The relevant provisions of the CSA provide criminal penalties for physicians who dispense controlled substances beyond "the course of professional practice," 21 U.S.C. § 802(21), see id. § 841(b), and provide for revocation of the DEA drug registrations of physicians who have engaged either in such criminal conduct or in other "conduct which may threaten the public health and safety," id. § 823(f). Because these terms are not further defined by the statute, we must look to the purpose of the CSA to understand their scope.

The CSA was intended to keep legally available controlled substances within lawful channels of distribution and use. See S. Rep. No. 91-613, at 3 (1969). It sought to prevent both the trafficking in these substances for unauthorized purposes and drug abuse. The particular drug abuse that Congress intended to prevent was that deriving from the drug's "stimulant, depressant, or hallucinogenic effect on the central nervous system," 21 U.S.C. § 811(f).

The Honorable Orrin G. Hatch
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There 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. Indeed, the CSA is essentially silent with regard to regulating the practice of medicine that involves legally available drugs (except for certain specific regulations dealing with the treatment of addicts, see 42 U.S.C. § 257a; 21 C.F.R. § 291.505).

Even more fundamentally, there is no evidence that Congress, in the CSA, intended to assign DEA the novel role of resolving the "earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide," Washington v. Glucksberg, 117 S. Ct. 2258, 2275 (1997), simply because that procedure involves the use of controlled substances. If Congress had assigned DEA this role under the CSA, it would ultimately be DEA's task to determine whether assistance in the commission of a suicide, in compliance with a state law specifically permitting and regulating such assistance, nevertheless falls outside the legitimate practice of medicine and is inconsistent with the public interest. These questions, however, are not susceptible of scientific or factual resolution, but rather are fundamental questions of morality and public policy. Such a mission falls well beyond the purpose of the CSA.

The state of Oregon has reached the considered judgment that physician-assisted suicide should be authorized under narrow conditions and in compliance with certain detailed procedures. Under these circumstances, we have concluded that the CSA does not authorize DEA to prosecute, or to revoke the DEA registration of, a physician who has assisted in a suicide in compliance with Oregon law. We emphasize that our conclusion is limited to these particular circumstances. Adverse action under the CSA may well be warranted in other circumstances: for example, where a physician assists in a suicide in a state that has not authorized the practice under any conditions, or where a physician fails to comply with state procedures in doing so. However, the federal government's pursuit of adverse actions against Oregon physicians who fully comply with that state's Death with Dignity Act would be beyond the purpose of the CSA.

Finally, notwithstanding our interpretation of the CSA as it applies to the Oregon Act, it is important to underscore that the President continues to maintain his longstanding position against assisted suicide and any Federal support for that procedure. This position was recently codified when he signed the Assisted Suicide Funding Restriction Act last year. While states

The Honorable Orrin G. Hatch
Page 4

ordinarily have primary responsibility for regulating physicians, the President and the Administration nonetheless remain open to working with you and other interested members of Congress on this complex but extremely important issue.

Sincerely,



Janet Reno

cc: The Honorable Patrick J. Leahy, Jr.
Ranking Minority Member



Office of the Attorney General

Washington, D. C. 20530

June 5, 1998

The Honorable Henry J. Hyde
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Committee on the Judiciary
U.S. House of Representatives
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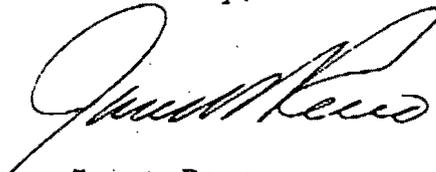
The Honorable Henry J. Hyde

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Sincerely,



Janet Reno

cc: The Honorable John Conyers, Jr.
Ranking Minority Member

THE
CATHOLIC HEALTH
ASSOCIATION
OF THE UNITED STATES

July 1, 1996

TO: Melanne Verveer
Deputy Assistant to the President and Deputy Chief of Staff to
the First Lady

FROM: Jack Bresch
Catholic Health Association

SUBJ: *Supportive Care of the Dying: A Coalition of Compassionate Care*



In light of the growing national debate about physician-assisted suicide, I thought the First Lady might be interested in learning about an innovative and collaborative effort by a number of Catholic health care systems and the Catholic Health Association of the United States (CHA) with regard to the issue of inadequate care of the dying.

When physician-assisted suicide was legalized by voters in Oregon in 1994, it became clear that public concern about the way modern medicine cares for the dying was at an all-time high. The fact that three juries acquitted Dr. Kevorkian of wrongfully assisting individuals to commit suicide demonstrates Americans' increasing fear of dying in intractable pain.

This public outcry prompted three Catholic-sponsored health care systems in Oregon¹ to come together to respond to public concerns. Joined later by three additional organizations,² they formed *Supportive Care of the Dying: A Coalition of Compassionate Care (SCD:CCC)*. Their shared goal is to ensure that compassionate, holistic supportive (palliative) care is provided to all people who need it. This effort honors individual values, diverse cultural attitudes and norms, the integrity of the human spirit, a demand for autonomy, the sacredness of life's final phase, and the reality of shrinking resources in order to create cultural change in the way the U.S. health system cares for persons near the end of life. *SCD:CCC* challenges and enables our health care system to move to person-centered and family-centered care in both traditional and non-traditional community settings.

WASHINGTON OFFICE

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¹ Franciscan Health System (now Catholic Health Initiative), PeaceHealth System, and Providence Health System

² Carondelet Health System (St. Louis), the Daughters of Charity National Health System (St. Louis) and the Catholic Health Association

The coalition's plan is three-pronged involving:

- research into actual needs of persons with life-threatening illness, their families, and communities;
- development of a comprehensive supportive (palliative) care model; and
- piloting a mentorship program for health care professionals that encourages and rewards holistic and compassionate care for people affected by life-threatening illness.

First, research conducted through focus groups will identify the needs and expectations of persons with life-threatening illness. Fifty focus groups across the United States will be organized into separate categories of persons with current life-threatening illness, their family members, and members of bereaved families, professional caregivers, and community members with little or no experience with death or dying.

Next, findings derived from this research will be used to develop a new model of care that supports individuals with life-threatening illness from the point of diagnosis through the trajectory of illness, dying, death and bereavement. The new model will focus on providing person-centered and family-centered care, whether that involves "healing into wellness" or "healing into dying."

Finally, interdisciplinary teams of chaplains, nurses, pharmacists, physicians, and social workers will meet with colleagues across the U.S. to mentor one another in the skills, knowledge, attitudes, and behaviors of this new culture of caring. These teams will be able to reach out to colleagues in both traditional settings (i.e., acute care hospital, home care programs, outpatient clinics, and long-term care facilities) as well as non-traditional settings (i.e., schools, industry, homeless shelters, churches, and social service agencies³).

³

SCD:CCCs not in competition with the hospice program. Hospice has made great strides in compassionate care of the dying, but its services generally are limited to individuals who have six months or less to live. The average terminally ill person spends only 52-56 days in the care of the hospice program. This limits greatly the person's and the family's ability to benefit from the positive support the service has to offer. Also, only 10 to 12 percent of terminally ill individuals enroll in hospice programs in the United States.

Melanne Verveer
Page Three

Funding for *SCD:CCC* relies in great part on the resources of the five member systems and CHA. The members are contributing either financially and/or with in-kind services or staff time to ensure the success of the coalition's efforts. The Project on Death in America (Open Society Institute) has recently approved a \$50,000 grant, and *SCD:CCC* has applied for a grant from the Robert Wood Johnson Foundation. In a spirit of bipartisan support, Congress has recommended that the HHS Agency for Health Care Policy and Research give full consideration for a grant to *SCD:CCC*.

Supportive Care of the Dying: A Coalition of Compassionate Care acknowledges that the responsibility for cultural change in health care can and must begin with Catholic health care. It accepts the challenge of integrating the best of health care with realities in our communities in a coordinated effort to promote respect and dignity for persons experiencing life-threatening illness, dying, death, and bereavement. *SCD:CCC* does this with full acknowledgment that for some we can cure, for others we cannot, but for all we can provide respect and dignity, and compassionate care and comfort all the days of the journey.

enclosure: "Danger Signs: Coalition Points to Causes and Consequences of Inadequate Care of the Dying," Health Progress, March/April 1996.

cc: Alexis M. Herman, Assistant to the President and Director, Public Liaison
Marilyn Yager, Deputy Assistant to the President and Deputy Director, Public Liaison

DANGER SIGNS

Coalition Points to Causes and Consequences Of Inadequate Care of the Dying

BY ALICIA SUPER, RN,
& LAWRENCE A.
PLUTKO



Ms. Super, a pain consultant at Providence/Portland Medical Center, Portland, OR, is project coordinator of Supportive Care of the Dying: A Coalition for Compassionate Care. Mr. Plutko, director of the Office of Theology and Ethics, Sisters of Providence Health System, Seattle, is chairperson of the coalition. This is the first in a series of articles on the coalition's activities.

At least 80 percent of the deaths in the United States occur in inpatient settings, primarily acute care hospitals. Only 10 percent to 12 percent of dying persons enroll in hospice programs. Although most healthcare resources and quality improvement efforts are targeted toward curative therapy, the fact remains that human beings die. Unfortunately, much like the greater community, healthcare professionals avoid dealing with death and dying and are unaware that care of the dying may be grossly inadequate.

Healthcare facility leaders should examine their organization for indications that care of the dying may be inadequate (see Box on p. 51). For those who find such danger signs, this article outlines the factors that lead to inadequate care and some steps that can help relieve the problem.

BARRIERS TO ADEQUATE CARE

Patients and families repeatedly express their need for supports based on compassion and caring, yet

healthcare efforts focus on often ineffective technological interventions and procedures. Those services which do exist for end-of-life care are based on clinician and physician *assumptions* about what dying persons and families need, rather than their *actual* assessed needs.

Lack of Training Physicians enter their profession with the goals of curing, promoting living, and applying new science to physical healing. Professional healthcare schools provide little or no formal training in pain and palliative symptom management or in the multidimensional approach to care of the dying. Unable to recognize the dying process (see Box on p. 52), physicians often transfer patients to intensive care units, where the natural process is seen as a medical complication. They aggressively battle medical complications with ventilators, dialysis, surgeries, and other technological interventions—only prolonging an inevitable death.

Lack of Time The pace of change in healthcare is pushing physicians and other professionals to

Summary Dying patients and their families repeatedly express their need for supports based on compassion and caring, yet healthcare efforts focus on often ineffective technological interventions and procedures. Professional healthcare schools provide little or no formal training in pain and palliative symptom management or in the multidimensional approach to care of the dying. And the pace of change in healthcare leaves little time for communication between the patient, family, and caring team. Physician denial of death and dying has a significant impact on clinical decision making and misleads healthcare administrators about priorities.

Even when clinicians want to practice holistic supportive care, they are often unable to because of competing productivity demands and lack of

reimbursement. Inappropriate therapies may be initiated to justify continued care in acute and skilled nursing environments. Because healthcare professionals may not inform families about what can be done in the way of supportive care, they may choose to "do everything," which often means using inappropriate treatments.

Supportive Care of the Dying: A Coalition for Compassionate Care is a unique collaborative effort to help change the culture of dying in healthcare and to help Catholic and other organizations offer appropriate care based on respect for the sanctity of life, regard for human dignity, and a commitment to stewardship. The coalition intends to develop a comprehensive supportive care model built on Catholic values and tradition.



treat more patients in less time using fewer resources. This leaves little time for high-quality communication between the patient, family, and caring team. Many medical residents report exhaustion and severely diminished empathy during their training as a result of long hours; unreasonable caseloads; and unrealistic expectations of superiors, hospital staff, and patients themselves.

A medical resident recently complained to us that he had become "mean" because of the pressures of his residency program. This young physician openly grieved over his decreased sympathy and empathy with patients. He said he would not survive his residency if he continued to care, to show compassion, and to advocate for patients who needed more time and multidimensional support. And he feared he would not be able to regain his empathy once his residency was complete.

Physician Denial Healthcare professionals regularly witness pain, suffering, and death in an environment that discourages acknowledgment of these events. Physicians, in particular, are groomed in medical schools to remain somewhat distant and aloof from such realities. While nurses may have opportunities to express feelings about a patient's death, physicians are often left out of such debriefings or avoid such interactions with non-physician colleagues. This practice promotes continued denial of death and dying among healthcare professionals. As noted in a recent study, denial has a significant impact on clinical decision making and misleads healthcare administrators about priorities.

Lack of Reimbursement Even when clinicians want to practice holistic supportive (palliative) care, they are often unable to because of competing productivity demands and lack of reimbursement. Healthcare resources are almost exclusively targeted for curative intervention; end-of-life care is a low priority. Revenue-generating services are highly valued in the healthcare system, but we commonly fail to measure end-of-life care against a different template of resource sharing and indirect revenue production.

Even when dying is recognized and the healthcare team has communicated this to the family, inappropriate therapies may be initiated to justify continued care in acute and skilled nursing environments. The natural dying process includes progressive inability to swallow, a reduction in renal function, and subsequent inability for the body to handle fluids. When artificial means of infusing fluids are used in dying patients, the

potential for pulmonary edema is heightened. However, when faced with the choice of (1) allowing intravenous feedings or fluids to justify insurance coverage for continued acute care or skilled nursing facility placement, or (2) allowing the natural dying process to proceed and paying privately for care in intermediate care facilities or at home with hired care givers, a family often opts (with the healthcare team's encouragement) for the former.

DANGER SIGNS

Review the following "danger signs" that care of the dying may be inadequate; note how many are present in your system.

- Patients are dying in acute care facilities without family and staff communication about the impending death.
- Healthcare staff uses "sanitized" language for death and dying (e.g., "the patient has expired," "the patient is gone").
- There is no routine monitoring of outcomes for care of the dying.
- A general assumption exists that local hospice programs have "got the problem covered."
- Physicians cite fear of litigation as the rationale for transferring dying patients to intensive care units.
- Administrators rely on professional education alone to change clinical practice.
- The words "There's nothing more we can do" are commonly used in reference to a dying person.
- Clinicians believe that all patients or families must make decisions about cardiopulmonary resuscitation.
- No support is available for healthcare professionals who work with dying persons and their families.
- The house staff is exhausted.
- No formalized bereavement follow-up is offered to survivors of persons who died as inpatients.
- No diagnosis-related group exists for supportive (palliative) care.
- No routine spiritual assessment is included in the patient record.
- Board of directors never asks and is never told about challenges healthcare professionals face in dealing with care of the dying.
- Average length of stay in hospice program is less than 120 days.
- Artificial nutrition and hydration are commonly initiated when dying patient loses ability to swallow.
- Physicians believe that patient deaths mean "physician failure."
- Everyone believes that completion of advance directives will solve problems listed above.

Did you find more than three or four "danger signs" in your system? If so, the risks of pain and suffering are very great. We urge you to champion change in your system's culture of caring for persons with life-threatening illness.

Likewise, although 85 percent to 95 percent of pain can be adequately managed by the oral or rectal administration of analgesics and adjuvant medications and other "low-tech" interventions, more costly intravenous infusions may be initiated to support skilled care. Clinicians are not promoting these interventions because they want to overtreat patients or inappropriately utilize resources; they may believe they are acting in the best interest of their patients and families. Many clinicians are not aware of the availability of comprehensive supportive care, and, moreover, it is *not* available in many communities.

Although hospice programs routinely provide

Many clinicians are not aware of the availability of supportive care.

emotional, spiritual, and social support to patients and families during illness, and bereavement support to the family after the patient's death, acute care and long-term care facilities rarely provide these services. The crisis of losing a loved one without support and empathetic assistance can lead to complicated grief. Isolation and abandonment during bereavement often lead to increased risk of

morbidity and mortality for surviving family members.

Families' Role in Decision Making Another factor often increasing the use of inappropriate technologies that only prolong the dying process is the patient's and family's involvement in decision making. By asking patients and families to "choose" whether to use a therapy such as ventilation or dialysis, physicians imply there is a choice. Our deceptive presentation of "odds" (e.g., a "5 percent chance of surviving" versus a "95 percent chance of dying" with a certain treatment) influences patient and family decisions. When possible benefits and burdens are clearly and fairly represented, patients may choose to forgo inappropriate treatment. However, many families cannot bear to think they are "allowing" their loved one to die and urge the physician to "do everything." Because healthcare professional may not be aware of or fail to inform families about what can be done in the way of supportive care (keeping people comfortable while they die naturally of disease), "doing everything" often means utilizing inappropriate treatments.

Physicians and other healthcare professionals may erroneously believe they are at risk of litigation if they refuse to follow family directives even when interventions are blatantly futile. In many situations, when patients have communicated their wishes to the physician and have written directives to avoid inappropriate treatment at the end of life, physicians still will treat the patient when families demand it. Not only is this a direct violation of the person's informed choice (with possible legal ramifications), it also places undue burden on the family when this treatment must

PHYSICAL MANIFESTATIONS OF THE DYING PROCESS

When death is the expected outcome, the following signs and symptoms are seen as natural occurrences, rather than medical complications to be obstructed or prolonged:

- Dying person refuses food . . .
- Increasing weakness . . .
- Social withdrawal (refusing visits from neighbors and friends) . . .
- Somnolence (increased sleepiness regardless of whether a person is taking opioids for pain or symptom management) . . .
- Voice initially hoarse, then a whisper . . .
- Refuses fluids . . .
- Emotional withdrawal from loved ones . . .
- Dysphagia (progressive inability to swallow) . . .
- Decreasing blood pressure . . .
- Increasing pulse (initially) . . .
- Cool, moist extremities . . .
- Decreasing pulse . . .
- Mottling (a purplish color variation in skin indicating decreased circulation) . . .
- Cheyne-Stokes respirations (an uneven respiratory pattern with progressively prolonged pauses) . . .
- Cessation of respiration . . .
- Cessation of heartbeat . . .



ultimately be discontinued to allow the patient to die.

A complicated bereavement follows for families who believe they have betrayed their loved ones by forcing unwanted treatment on them or ultimately deciding to stop treatment. Some family members actually feel they have made a decision to "kill" their loved ones by allowing the physician to discontinue a ventilator or some other death-prolonging technology.

SUPPORTIVE CARE OF THE DYING

Supportive Care of the Dying: A Coalition for Compassionate Care is a unique collaborative effort to help change the culture of dying in healthcare and to help Catholic and other organizations offer appropriate care based on respect for the sanctity of life, regard for human dignity, and commitment to stewardship. (See Box.)

Although the coalition's title refers to dying, the six member organizations recognize that the best way to care for the dying is to intervene much earlier. The trajectory of illness begins at the time of diagnosis of a life-threatening illness and ends after comprehensive bereavement care for the family after the patient's death (see Figure, p. 54).

The coalition intends to develop a comprehensive supportive care model that could be implemented in any healthcare organization across the United States. The model will be piloted in selected Catholic healthcare settings, but information will be shared outside of Catholic healthcare as well. Although this model is being built on Catholic values and tradition, the permeable model boundaries will allow a respectful balance between community and individual values, norms, and expectation.

Unlike the current situation in which persons are viewed as "patients" who must come to the healthcare system for care, the supportive care model will promote service to persons in their own supportive environments. This will require that such services move beyond the traditional "walls" and into industry, schools, churches, homes, social service agencies, and rural environments. Services will be tailored to individual and community needs and be supported by health benefits and payer systems.

The supportive care model will be person and family centered rather than disease and physician centered. A dynamic care plan will be developed jointly by the person with life-threatening illness, the family (of origin and/or choice), the interdis-

ciplinary healthcare team, and community supports.

High-priority, high-quality supportive care is not only the "right" thing to do, it also promotes improved patient and family coping and satisfaction, enhances job satisfaction for healthcare professionals, creates an "environment of care" that serves the entire system and community, and generates indirect revenue in the form of individual and industry donations to system foundations and community service agencies.

COALITION WORK IN PROGRESS

While the coalition is building and testing the model, intermediate products will be available. An initial product is a needs assessment. Various focus group sessions to be held across the country between March and June will elicit from five targeted groups the actual information, program, and service needs of individuals dealing with life-threatening illness. The focus group methodology is now being piloted in sessions with:

- Persons with current life-threatening illness
- Personal care givers (family, friends, volunteers)
- Bereaved family members
- Professional care givers of persons with life-

SUPPORTIVE CARE OF THE DYING: A COALITION FOR COMPASSIONATE CARE

The Supportive Care of the Dying coalition was founded in 1995 by the Catholic Health Association and five Catholic healthcare systems: Carondelet Health System, St. Louis; Daughters of Charity National Health System, St. Louis; Franciscan Health System, Aston, PA; PeaceHealth, Bellevue, WA; and Providence Health System, Seattle. The coalition's goals are to:

- Assess the current level of care to identify, develop, and share delivery models pertaining to all dimensions of care for the suffering and dying
- Develop and implement a paradigm of compassionate care that integrates ethical, clinical, and spiritual dimensions
- Develop educational programs for professional care givers, families, and the broader community
- Establish criteria and measurement guidelines to assess processes, outcomes of education, compassionate care services, and methods of assigning accountability for these guidelines and processes
- Foster networking among care givers and identify resources within the broader community that support compassionate care of persons with life-threatening illness

threatening illness

- Community members with little or no experience with death or dying

Information gained from the needs assessment will be used to improve the recommended model of supportive care in order to produce information, programs, and services that more appropriately and directly address needs. These include:

- Education and training modules
- Hands-on mentor program to ensure assimilation of new knowledge and skills into current clinical practice
- Guidelines for both clinical practice and leadership competencies to promote excellence and a high profile for end-of-life care and resource allocation
- A quarterly project newsletter, *Supportive Voice*, to keep members and the broader community abreast of progress and developments (The first edition of the newsletter was mailed in the first quarter of 1996.)

BEYOND ASSUMPTIONS

Until we know more about the actual needs of persons living the experience of life-threatening illness, we risk both underserving persons in need and overutilizing expensive resources for inappro-

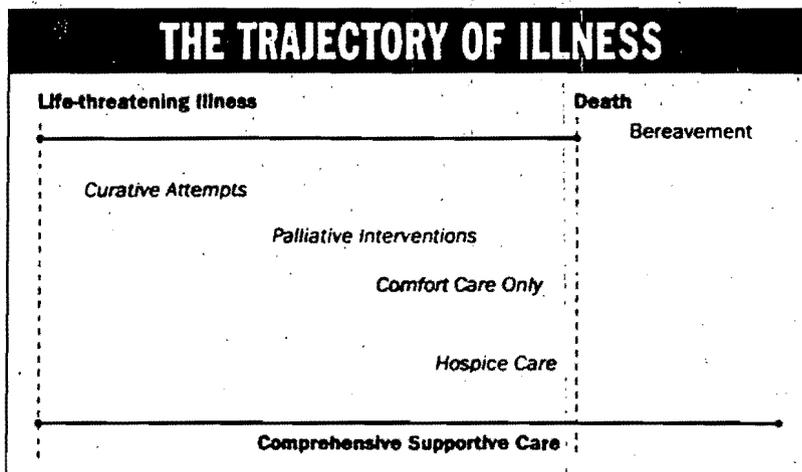
Leaders must change the culture of death and dying in the United States.

priate care. Advance directives, software to facilitate clinical decision making, and physician-assisted suicide initiatives are smokescreens to avoid dealing with death and dying and to provide the illusion of control with end-of-life issues. Laws, documents, and blips on computer monitors cannot facilitate the kind of care people really want and need when faced with life-threatening illness.

Just as the care of this population requires time and commitment from compassionate, skillful clinicians and welcoming communities, the training for and implementation of this care will require permanent change and committed resources. Hence leaders in healthcare, government, and local communities must assume their proper advocacy roles to change the culture of death and dying in the United States and bring to life these words from the coalition's vision statement:

In a manner consistent with Catholic teaching, we believe that patients have a right to maximal comfort regardless of the stage of their disease or their life expectancy. We are committed to providing quality care in a way that alleviates pain and minimizes suffering.

We are committed, as well, to establishing and maintaining standards whereby physicians and other members of the healthcare team will be held accountable in working toward this goal. Interdisciplinary clinical teams are an effective antidote to fragmentation of care, while promoting accountability. As values-based organizations we are committed to focusing our energies and to providing resources to further enhance the visibility of this issue within our healthcare systems and beyond. □



☎ For more information on the coalition, or to receive the newsletter, contact Project Coordinator Alicia Super, Providence Health System, 4805 NE Glisan St., 2E09, Portland, OR 97213-2967; 503-215-5053.

THE ASSISTED SUICIDE FUNDING RESTRICTION ACT OF 1997

What does the bill do?

The bill ensures that federal tax funds are not used to pay for and promote assisted suicide or euthanasia. Section 2, the "General Prohibition on Use of Federal Assistance," prevents funding for items or services "the purpose of which is to cause, or assist in causing, the suicide, euthanasia, or mercy killing of any individual."

The bill then identifies those federal programs from which funds cannot be used to support assisted suicide, including Medicare, Medicaid, Federal Employees Health Benefits (FEHB) plans, medical services for federal prisoners, and the military health care system.

In addition, the bill amends the Patient Self-Determination Act to clarify that federal law does not impose a mandatory requirement on health care facilities in states where assisted suicide has been legalized to advise every patient upon admission about his or her "right" to obtain lethal drugs for suicide.

Why is the bill needed?

On January 8, 1997, the Supreme Court heard oral arguments in two cases in which federal courts of appeal have declared a constitutional right to assisted suicide. In the state of Oregon, in which assisted suicide has been legalized by referendum, officials have stated that Medicaid dollars will be used to fund assisted suicide once its law, currently in litigation, goes into effect. The question of whether federal funds and facilities will be used to fund and promote assist suicide could arise in any jurisdiction in which it is legalized.

Does the bill affect withholding of medical treatment, nutrition, or pain relief?

The Assisted Suicide Funding Restriction Act does not create any limitation regarding the withholding or withdrawing of medical treatment or of nutrition or hydration, nor does it affect funding for abortion or for alleviating pain or discomfort for patients. The Rule of Construction in Section 3 removes any doubt on this score.

Where does President Clinton stand on assisting suicide?

When asked in the 1992 campaign about legislation to allow assisted suicide, President Clinton said, "I certainly would do what I could to oppose it." On November 12, 1996, the Clinton Administration filed "friend of the court" briefs with the Supreme Court in opposition to physician-assisted suicide. In the brief for the Administration, Solicitor General Walter Dellinger wrote, "There is an important and common-sense distinction between withdrawing artificial supports so that a disease will progress to its inevitable end, and providing chemicals to be used to kill someone."

Where does the public stand on taxpayer funding of assisted suicide?

87% answered "No" when asked, "Should tax dollars be used to pay for the cost of assisting suicide and euthanasia?" in a national Wirthlin poll in November, 1996.

United States Senate

WASHINGTON, DC 20510

January 8, 1997

ASSISTED SUICIDE FUNDING RESTRICTION ACT

Dear Colleague:

Today the Supreme Court will hear oral arguments in two cases, *Washington v. Glucksberg* and *Vacco v. Quill*. Both of these cases involve the question of whether there is a constitutional right to assisted suicide. While the fundamental issues before the Court are complex and controversial, there is one point on which an overwhelming majority of Americans agree: 87% of the public believes that tax dollars should not be spent to pay for assisting suicide or euthanasia. Regardless of their personal views about this practice, taxpayers clearly regard federal funding of assisted suicide as inappropriate.

We intend to introduce legislation early in this Congress, the Assisted Suicide Funding Restriction Act of 1997, that would ensure that federal tax dollars are not used to fund or promote assisted suicide. This bill was introduced at the end of the 104th Congress in both the House and Senate and had significant bipartisan support in both bodies. The legislation does not attempt to answer the complex question of whether assisted suicide should be legalized – it simply prevents federal funds and federal programs from being drawn into promoting and paying for it.

Without this bill, taxpayer funding of assisted suicide could be imminent. Oregon has passed legislation to legalize physician assisted-suicide, and the state's Medicaid director has already announced that the state will begin subsidizing assisted suicide through Medicaid once the legal challenges to its law have been resolved. We don't believe this has ever been Congress' intention, and we should not stand idly by and allow it to happen.

If you would like to join us in cosponsoring this bill when we introduce it, or if you have any questions, please call one of us or have your staff contact either Stephanie Mohl with Sen. Dorgan at 4-2551 or Annie Billings with Sen. Ashcroft at 4-6154.

Sincerely,


Byron L. Dorgan
U.S. Senator


John Ashcroft
U.S. Senator

MEMORANDUM

January 21, 1997

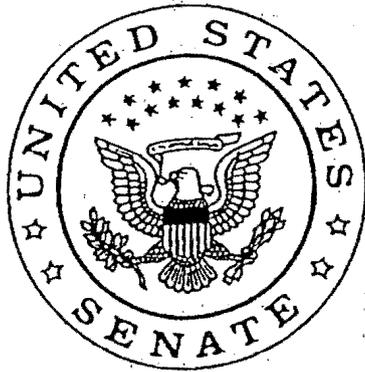
TO: Chris Jennings
FR: Stephanie Mohl, Legislative Assistant for Sen. Byron Dorgan
RE: Sen. Dorgan's Assisted Suicide Funding Restriction Act

Chris, I'd like to talk with you briefly about getting the Clinton Administration's endorsement for Senator Dorgan's Assisted Suicide Funding Restriction Act. As you may know, this is a bill (S. 2108) that my boss introduced at the end of the 104th Congress, with bipartisan support, to prohibit the use of federal funding to pay for physician-assisted suicide, and he intends to re-introduce it early in the 105th. The bill covers all federal health programs: Medicare and Medicaid are obviously the big ones, but it also includes FEHB plans, IHS, defense and veterans health facilities, etc.

Since the Administration has already announced its opposition to assisted suicide through the amicus curae briefs it filed with the Supreme Court, opposing federal funding for this practice would be consistent with that position. Also, recent polls suggest that an overwhelming majority of Americans (87%), regardless of their personal views on this issue, don't believe assisting in suicide is an appropriate use of federal tax dollars.

This is legislation that should be non-controversial and garner support from all portions of the political spectrum. We're not aware of opposition and view this bill as a good opportunity for Democrats and Republicans to demonstrate that they can work together to accomplish something the American people support.

I'm sending along Senator Dorgan's Dear Colleague and a summary of the bill. After you've had a chance to look this over, I'd appreciate your giving me a call at 224-3488 to discuss the Administration's support.



United States Senate
U.S. Senator Byron L. Dorgan
713 Hart
Washington, D.C. 20510
202-224-2551

To: Name: Jason Wolin
Organization: Chris Jennings' office
FAX #: 456-7431
Phone Number: 456-5560

From: Name: Stephanie Mohl
FAX #: _____
Phone Number: 224-3488

Comments:

MEMORANDUM
December 18, 1996

TO: Chris Jennings
FR: Stephanie Mohl, Legislative Assistant for Sen. Byron Dorgan
RE: Sen. Dorgan's Assisted Suicide Funding Restriction Act

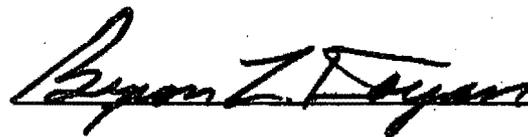
Chris, I'd like to talk with you briefly about getting the President's endorsement for Senator Dorgan's Assisted Suicide Funding Restriction Act. As you may know, this is a bill that my boss introduced at the end of the 104th Congress, with bipartisan support, to prohibit the use of federal funding to pay for physician-assisted suicide. The bill covers all federal health programs: Medicare and Medicaid are obviously the big ones, but it also includes FEHB plans, IHS, defense and veterans health facilities, etc.

Since the Administration has already announced its opposition to assisted suicide through the amicus curae briefs it filed with the Supreme Court, opposing federal funding for this practice would be consistent with that position. Also, recent polls suggest that an overwhelming majority of Americans (87%), regardless of their personal views on this issue, don't believe assisting in suicide is an appropriate use of federal tax dollars.

This is legislation that should be non-controversial and garner support from all portions of the political spectrum. We're not aware of opposition and view this bill as a good opportunity for Democrats and Republicans to demonstrate that they can work together to accomplish something the American people support.

I'm sending along Senator Dorgan's floor statement from earlier this year, which further describes the bill and the need for it. After you've had a chance to look this over, I'd appreciate your giving me a call at 224-3488 to discuss this further.

*Thanks!
Stephanie*



THE ASSISTED SUICIDE FUNDING RESTRICTION ACT

Mr. DORGAN. Mr. President, I rise today to introduce legislation, along with Senator Ashcroft, that will prohibit Federal funds from being used for the costs associated with assisted suicide.

I understand that the decisions that confront individuals and their families when a terminal illness strikes are among the most difficult a family will ever have to make. At times like this, each of us must rely on our own religious beliefs and conscience to guide us. But regardless of one's personal views about assisted suicide, I do not believe that taxpayers should be forced to pay for this controversial practice. The majority of taxpayers I have talked to do not want their tax money used to assist in suicides. In fact, when asked in a poll in May of this year whether tax dollars should be spent for assisting suicide, 83 percent of taxpayers feel tax money should not be spent for this purpose.

The Assisted Suicide Funding Restriction Act prevents any Federal funding from being used for any item or service which is intended to cause, or assist in causing, the suicide, euthanasia, or mercy killing of any individual. The programs covered under this bill include Medicare, Medicaid, the military health care system, Federal Employees Health Benefits (FEHB) plans, Public Health Service programs, programs for the disabled, and the Indian Health Service.

This bill does make some important exceptions. First, let me make clear that this bill does not limit the withholding or withdrawal of medical treatment or of nutrition or hydration from terminally ill patients who have decided that they do not want their lives sustained by medical technology. Most people and states recognize that there are ethical, moral, and legal distinctions between actively taking steps to end a patient's life and withholding or withdrawing treatment in order to allow a patient to die naturally. Every state now has a law in place governing a patient's right to lay out in advance, through an "advanced directive," "living will," or some other means, his or her wishes related to medical care at the end of life. Again, this bill would not interfere with the ability of patients and their families to make clear and carry out their wishes regarding the withholding or withdrawal of medical care that is prolonging the patient's life.

This bill also makes clear that it does not prevent Federal funding for any care or service that is intended to alleviate a patient's pain or discomfort, even if the use of this pain control ultimately hastens the patient's death. Large doses of medication are often needed to effectively reduce a terminally ill patient's pain, and this medication may increase the patient's risk of death. I think we all would agree that the utmost effort should be made to ensure that terminally ill patients do not spend their final days in pain and suffering.

Finally, while I think Federal dollars ought not be used to assist a suicide, this bill does not prohibit a state from using its own dollars for this purpose. However, I do not think taxpayers from other states, who have determined that physician-assisted suicide should be illegal, should be forced to pay for this practice through the use of Federal tax dollars.

I realize that the legality of assisted suicide has historically been a state issue. Thirty-five states, including my State of North Dakota, have laws prohibiting assisted suicide and at least eight other states consider this practice to be illegal under common law. Only one state, Oregon, has a law legalizing assisted suicide.

However, two circumstances have changed that now make this an issue of Federal concern. First, Federal courts are already handing down decisions that will have enormous consequences on our public policy regarding assisted suicide. Second, we are on the brink of a situation where Federal Medicaid dollars may soon be used to reimburse physicians who help their patients die. Should this occur, Congress will not have considered this issue. I believe it was never Congress' intention for Medicaid or other Federal dollars to be used to assist in suicide, and I hope we will take action soon to stop this practice before it starts. If Congress does not act, a few states, or a few judges, may very well make this decision for us.

In two separate cases this year, *Compassion in Dying v. State of Washington* and *Quill v. Vacco*, the Federal Ninth and Second Circuit Courts of Appeal, respectively, have struck down Washington and New York State statutes outlawing assisted suicide. In the *Compassion in Dying* case, the Ninth Circuit held that the "right to die" is Constitutionally recognized and that Washington State's law prohibiting physicians from prescribing life-ending medication therefore violates the "due process" clause of the Fourteenth Amendment for terminally ill adults who wish to end their life. In *Quill v. Vacco*, the Second Circuit also found that a state law prohibiting physician-assisted suicide violates the Constitution, but it did not agree with the Ninth Circuit's reasoning that such a law violates the due process clause. Rather, the Second Circuit held that the New York State law was unconstitutional because it violates the "equal protection" clause of the Constitution. The Supreme Court could decide to take up one or both of these cases as early as next year.

Ironically, in a third case, *Lee v. Oregon*, a Federal district court judge also used the "equal protection" clause as the basis for his decision -- but he ruled that Oregon's 1994 law allowing assisted suicide for the terminally ill violates the Constitution, and the judge enjoined the implementation of Oregon's law. However, this decision has been appealed to the Ninth Circuit Court of Appeals, which has already affirmed a Constitutional "right to die." The Ninth Circuit's decision, which is expected to overturn the district court and lift the injunction against Oregon's law, could be handed down any day. The State's Medicaid director has already stated that, when the injunction against Oregon's law is lifted, Oregon will use

Medicaid dollars to pay for the costs associated with a physician assisting in suicide.

I hope you agree with me and the vast majority of Americans who oppose using scarce Federal dollars to pay for assisted suicide. I invite you to join me, Senator Ashcroft and 14 of our colleagues in this effort by cosponsoring the Assisted Suicide Funding Restriction Act.

THE ASSISTED SUICIDE FUNDING RESTRICTION ACT OF 1996

What does the bill do?

The bill ensures that federal tax funds are not used to pay for and promote assisted suicide or euthanasia. Section 2, the "General Prohibition on Use of Federal Assistance," prevents funding items or services "the purpose of which is to cause, or assist in causing, the suicide, euthanasia, or mercy killing of any individual."

The bill then specifically spells out areas in which funds cannot be used: programs for individuals with disabilities, the public health service system, Medicaid, Medicare, long-term care ombudsman program, block grants to states for social services, Indian health care program, the military health care system, Federal Employees Health Benefits plans, health care for Peace Corps volunteers, medical services for federal prisoners, District of Columbia appropriations, and Legal Services. In addition, the bill amends the Patient Self-Determination Act to ensure that federal law does not impose a mandatory requirement on health care facilities in states where assisted suicide has been legalized to advise every patient upon admission about his or her "right" to obtain lethal drugs for suicide.

Why is the bill needed?

In cases likely soon to go before the U.S. Supreme Court, federal courts of appeal have declared a constitutional right to assisted suicide. In a state in which it has been legalized by referendum, officials have stated Medicaid dollars will be used to fund it should the law, currently in litigation, go into effect. The question of whether federal funds and facilities will be used to fund and promote assisted suicide will arise anywhere it becomes legal.

Does the bill affect withholding of treatment or pain relief?

The "Assisted Suicide Funding Restriction Act" does not create any limitation regarding the withholding or withdrawing of medical treatment or of nutrition or hydration, nor does it affect funding for alleviating pain or discomfort for patients. The Rule of Construction in Section 3 removes any doubt on this score.

Where does President Clinton stand on assisting suicide?

When asked in the 1992 campaign about legislation to allow assisted suicide, he said, "I certainly would do what I could to oppose it." On April 17, 1996, his spokeswoman Mary Ellen Glynn publicly reaffirmed to the press the President's opposition to assisted suicide.

Where does the public stand on tax funding of assisted suicide?

83% answered "No" when asked "Should tax dollars be spent to pay for the cost of assisting suicide and euthanasia" in a national Wirthlin Worldwide poll May 28-30, 1996 with a 3.1% margin of error.

DUF

DEPARTMENT OF HEALTH AND HUMAN SERVICES
ASSISTANT SECRETARY FOR PLANNING AND EVALUATION
OFFICE OF HEALTH POLICY



PHONE: (202) 690-6870 FAX: (202) 401-7321

Date:

From:

Jack Ebel

To:

Chris Jennings

Phone:

(202) 690-
(202) 690-6870

Phone:

FAX:

(202) 401-7321

Fax:

Number of Pages (Including Cover):

Comments:

7. ABORTION/ASSISTED SUICIDE

Key point: the restriction on abortion funding in Medicaid has never been included in the Medicaid statute - it has always been part of annual appropriations riders.

- The Republican plan would incorporate into permanent Medicaid law a restriction allowing funding for abortion for low-income women only to save life of mother or if pregnancy resulted from rape or incest.

8. FUNDING FORMULA

Key point: regardless of all the arguments about funding and flexibility, the reality is that their block grant caps the program at unsustainable federal funding levels.

- While Republicans claim their block grant formula gives states more equitable funding, in truth states get less -- and fixed -- funds.
- Their formula caps the program at less than 2 percent per year per capita growth according to CBO -- that is less than inflation, and 70 percent below private sector growth rates.
- The President's plan limits growth to 5.5 percent per capita -- and even that is less than private sector growth of 7 percent.
- As a block grant, their formula breaches the 30 year federal financial commitment to maintaining shared responsibility in financing the program with the states. The block grant is not adaptable to future economic changes and state decisions about enrollment changes
 - The President's per capita cap -- and the Coalition and Daschle plans -- adapt automatically to any such changes -- with continuing federal matching.
 - The block grant does not adapt -- it is a fixed amount -- and their recently added "Rainy Day fund" of \$16 billion over 7 years is inadequate to deal with recessions, and is dependent on future federal actions rather than adapting automatically to state changes as under the per capita cap.
- Their "back-loaded" cuts mean that the situation is worst in the out-years -- when annual growth rates per capita fall below 1 percent in 1999, and reach -1.7 percent in 2001.

9. DSH PAYMENTS

Key point: the President's plan, the Coalition plan, and the Daschle plan all provide for DSH reductions. The Coalition retargets the funds, and the Daschle plan phases in the retargeting. We are willing to move beyond our plan and negotiate revisions and retargeting of DSH.

- The Republican block grant does not retain the special disproportionate share hospital payment program (DSH) -- it includes those funds within the block grant.
- The Democratic plans all retain some DSH program -- with reductions as a major source of federal savings.
- The President's plan reduces DSH across the board -- with larger reductions from states that have high DSH spending, and lower reductions from states that have lower DSH spending. States are given greater flexibility in how to target these funds to providers such as federally-qualified health centers and rural health centers.
- The Coalition plan retargets DSH based on state and provider need; and the Daschle plan phases from the President's reductions to the Coalition retargeting.
- The Administration is willing to move to the Coalition and Daschle positions -- or other DSH methods -- to achieve savings as well target funds on DSH providers. However, this must be done in a careful manner to assure that individual states are not hurt too much by the funding cuts.

10. FLEXIBILITY - MANAGED CARE

Key point: the President's plan provides states with the flexibility they need to adopt managed care arrangements without the need for federal waivers. And, like the Coalition and Daschle plans, it includes quality standards.

- The President's plan provides substantial new areas of flexibility in developing and implementing mandatory managed care and primary care case management systems, without the need for a federal waiver.
- Individuals must still have a choice of plan (in urban areas -- this provision would not apply in rural areas) -- and quality standards would be required as well.
- This provides the states a key area of flexibility in how they operate their program and design their delivery system within the state -- without the need for waivers.

11. PROVIDER PAYMENTS

Key points: The President's plan would repeal the Boren amendment, as well as other special payment requirements.

- The Boren amendment -- a key problem for Governors -- is repealed in the President's plan (Note: the Coalition plan retains Boren).
- Other special payment requirements are repealed or phased out (cost-based payments for federally qualified health centers are phased-out over years; special payment reporting requirements for obstetrical and pediatric services are repealed).
- We have retained a requirement that payments to health plans be actuarially based (this is also included in the Republican plan).
- This payment flexibility, like the managed care flexibility, provides the states with the tools that they have requested to operate their programs within fiscal restraints -- while maintaining the entitlement to coverage.

12. FAMILY RESPONSIBILITY

Key point: the President's plan maintains important family financial protections -- including spousal impoverishment protections, and protections against liens. These are Medicaid family protection issues of importance not just to the poor, but a larger group of middle class families for whom Medicaid is a catastrophic safety net for long-term care for their parents.

- The Republicans claim that they are taking care of spousal impoverishment protections -- but since there is no guaranteed coverage for nursing home care, Medicaid need not pay at all -- leaving spouses unprotected.
- And, the Republicans would allow states to impose for the first time under Medicaid financial costs on the adult children of nursing home patients if they had income above the median state income.
- The President's plan maintains the financial protections for beneficiaries and families under Medicaid -- spousal protections, relative responsibility, and liens.

13. NURSING HOME STANDARDS

Key point: the Republicans claim to have retained the nursing home standards -- but by shifting to state enforcement, the bipartisan national consensus that was reached in the Reagan administration will be breached.

- The President's plan -- and all the other Democratic plans -- retain the 1987 bipartisan standards and enforcement models.
- The Republicans claim to maintain the standards -- but shift to state enforcement. That means that we will once again have 50 different approaches to nursing home quality -- breaching the national consensus reached in 1987.

Assisted Suicide Fb 001



Office of the Deputy Attorney General
United States Department of Justice
950 Pennsylvania Ave. NW
Washington, D. C. 20530

TO: Karen Popp

FAX: 456-5055

FROM: Jonathan D. Schwartz
Associate Deputy Attorney General

VOICE: (202) 305-8060
FAX: (202) 514-9368

Total Pages (excluding this cover): _____

Additional Message:

CLOSE HOLD

(addressing both statutory question and policy)
DRAFT

Dear Congressman Hyde:

This is in response to your letter urging the Department of Justice, through the Drug Enforcement Administration ("DEA"), to invoke the Controlled Substances Act ("CSA"), 21 U.S.C. §§ 801-971 (1994), to take adverse action against physicians who assist patients in ending their lives by prescribing controlled substances. The issue has arisen in the context of Oregon's "Death with Dignity Act," Oreg. Rev. Stat. §§ 127.800-127.995, which permits physicians to assist competent, terminally ill patients in ending their lives in compliance with certain detailed procedures. The Department has reviewed the issue thoroughly 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, or appropriate under, the CSA.

The Oregon Act was approved by Oregon voters on November 8, 1994, and went into effect on October 27, 1997. The Act provides for a detailed procedure by which a mentally competent, terminally ill patient may request to end his or her life "in a humane and dignified manner." O.R.S. § 127.805. The procedure requires, for example, that the patient's competence and the voluntariness of the request be documented in writing and confirmed by two witnesses, see id. § 127.810(1), that the patient's illness and competence and the voluntariness of the request be confirmed by a second physician, see id. § 127.820, and that the physician and patient observe certain waiting periods, see id. §§ 127.840, 127.850. Once a request has been properly documented and the requisite waiting periods have expired, the patient's attending physician may prescribe, but not administer, medication to enable the patient to take his or her own life. As a matter of state law, physicians acting in accordance with the Oregon Act are immune from liability as well as any adverse disciplinary action for having rendered such assistance.

Prior to the Oregon Act's taking effect last year, the chairmen of the House and Senate Judiciary Committees wrote to DEA Administrator Thomas Constantine seeking the DEA's view as to whether delivering, distributing, dispensing, prescribing, or administering a controlled substance with the intent of assisting in a suicide would violate the CSA notwithstanding a state law such as the Oregon Act. In response, Administrator Constantine explained that "physician-assisted suicide would be a new and different application of the CSA," and that the determination whether to pursue adverse action under the CSA would first require "a medico-legal investigation" involving "state and local law enforcement agencies and prosecutors." He also stated, however, that "the activities that you described in your letter to us would be, in our opinion, a violation of the CSA." Subsequently, many Members of Congress have sent letters urging that I support the DEA's conclusions and enforce federal laws and regulations

accordingly. I have received other correspondence supporting a contrary conclusion.

The Department has conducted a thorough and careful review of the issue of whether the CSA authorizes adverse action against a physician who prescribes a controlled substance to assist in a suicide in compliance with Oregon law, and whether such action would be appropriate.

The CSA is a complex regulatory scheme that controls the authorized distribution of scheduled drugs. Physicians, for example, are authorized to prescribe and distribute scheduled drugs only pursuant to their registration with the DEA, and the unauthorized distribution of drugs is generally subject to criminal and administrative action. The CSA provides criminal penalties for physicians who dispense controlled substances beyond "the course of professional practice," 21 U.S.C. § 802(21), and provides for the revocation of DEA drug registrations of physicians who have engaged either in such criminal conduct or in other "conduct which may threaten the public health and safety," *id.* § 823(f). Because these terms are not further defined by the statute, we must look to the purpose of the CSA to understand their scope.

The CSA was intended to keep legally available controlled substances within lawful channels of distribution and use. See S. Rep. No. 91-613, at 3 (1969). It sought to prevent both the trafficking in these substances for unauthorized purposes and drug abuse. The particular drug abuse that Congress intended to prevent was that deriving from the drug's "stimulant, depressant, or hallucinogenic effect on the central nervous system," 21 U.S.C. § 811(f).

There 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. Indeed, the CSA is essentially silent with regard to regulating the practice of medicine that involves legally available drugs (except for certain specific regulations dealing with the treatment of addicts, see 42 U.S.C. § 257a; 21 C.F.R. § 291.505).

Even more fundamentally, there is no evidence that Congress, in the CSA, intended to assign DEA the novel role of resolving the "earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide," Washington v. Glucksberg, 117 S. Ct. 2258, 2275 (1997), simply because that procedure involves the use of controlled substances. If Congress had assigned DEA this role under the CSA, it would ultimately be DEA's task to determine whether assistance in the commission of a suicide, in compliance with a state law specifically permitting and regulating such assistance, nevertheless falls outside the

legitimate practice of medicine and is inconsistent with the public interest. These questions, however, are not susceptible of scientific or factual resolution, but rather are fundamental questions of morality and public policy. Such a mission falls well beyond the purpose of the CSA.

Even if the CSA could be read to permit DEA to take adverse action against physicians in these circumstances, we would be hesitant to use the statute in a manner that falls so far from its core purpose. Given the purpose of the CSA, the traditional deference accorded states as the primary regulators of the medical profession, and the practical difficulty of assigning DEA this novel role in a state whose officials are enforcing a law permitting physician-assisted suicide, we would not take adverse action under the CSA against physicians in this situation.

The state of Oregon has reached the considered judgment that physician-assisted suicide should be authorized under certain conditions. We do not believe that the CSA authorizes DEA, or that it would be warranted for DEA, to pursue adverse criminal or administrative action against a physician who has assisted in a suicide in full compliance with Oregon law. We emphasize that our conclusion is limited to these narrow circumstances; adverse action under the CSA may well be warranted in other states when a physician assists in a suicide without state authorization, and indeed, in Oregon when a physician has failed to comply with Oregon law in doing so. However, the pursuit of such adverse action against a physician in Oregon who has fully complied with that state's Death with Dignity Act would go beyond anything Congress intended in crafting the CSA.

Sincerely,

Janet Reno

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(resolving statutory authority question,
but not addressing policy)

DRAFT

Dear Congressman Hyde:

This is in response to your letter urging the Department of Justice, through the Drug Enforcement Administration ("DEA"), to invoke the Controlled Substances Act ("CSA"), 21 U.S.C. §§ 801-971 (1994), to take adverse action against physicians who assist patients in ending their lives by prescribing controlled substances. The issue has arisen in the context of Oregon's "Death with Dignity Act," Oreg. Rev. Stat. §§ 127.800-127.995, which permits physicians to assist competent, terminally ill patients in ending their lives in compliance with certain detailed procedures. The Department has reviewed the issue thoroughly 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.

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DEA's conclusions and enforce federal laws and regulations accordingly. I have received other correspondence supporting a contrary conclusion.

The Department has conducted a thorough and careful review of the issue of whether the CSA authorizes adverse action against a physician who prescribes a controlled substance to assist in a suicide in compliance with Oregon law.

The CSA is a complex regulatory scheme that controls the authorized distribution of scheduled drugs. Physicians, for example, are authorized to prescribe and distribute scheduled drugs only pursuant to their registration with the DEA, and the unauthorized distribution of drugs is generally subject to criminal and administrative action. The CSA provides criminal penalties for physicians who dispense controlled substances beyond "the course of professional practice," 21 U.S.C. § 802(21), and provides for the revocation of DEA drug registrations of physicians who have engaged either in such criminal conduct or in other "conduct which may threaten the public health and safety," *id.* § 823(f). Because these terms are not further defined by the statute, we must look to the purpose of the CSA to understand their scope.

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Even more fundamentally, there is no evidence that Congress, in the CSA, intended to assign DEA the novel role of resolving the "earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide," Washington v. Glucksberg, 117 S. Ct. 2258, 2275 (1997), simply because that procedure involves the use of controlled substances. If Congress had assigned DEA this role under the CSA, it would ultimately be DEA's task to determine whether assistance in the commission of a suicide, in compliance with a state law specifically permitting and regulating such assistance, nevertheless falls outside the

legitimate practice of medicine and is inconsistent with the public interest. These questions, however, are not susceptible of scientific or factual resolution, but rather are fundamental questions of morality and public policy. Such a mission falls well beyond the purpose of the CSA.

The state of Oregon has reached the considered judgment that physician-assisted suicide should be authorized under certain conditions. Under these circumstances, we have concluded that the CSA does not authorize DEA to prosecute, or to revoke the DEA registration of, a physician who has assisted in a suicide in compliance with Oregon law. We emphasize that our conclusion is limited to these narrow circumstances; adverse action under the CSA may well be warranted in other states when a physician assists in a suicide without state authorization, and indeed, in Oregon when a physician has failed to comply with Oregon law in doing so. However, the pursuit of such adverse action against a physician in Oregon who has fully complied with that state's Death with Dignity Act would go beyond anything Congress intended in crafting the CSA.

Sincerely,

Janet Reno

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I plan protest assisted suicide



Koop: Doctors shouldn't be killers

petrified they will be next," says Stephen Gold, lawyer for the 20,000-member group Not Dead Yet and American Disabled for Attendant Programs Today.

Gold wrote a friend-of-the-court brief in the Supreme Court cases detailing how even now people with out-terminal illness are coerced into ending treatment. He says the problem would worsen if physician-assisted suicide were legalized.

"We want to express our fear and outrage in the streets," said Diane Coleman, co-founder of Not Dead Yet and director of the Progress Center for Independent Living in Forest Park, Ill.

The demonstrators will be addressed by former Surgeon General C. Everett Koop, who also opposes physician-assisted suicide.

"Society must not allow doctors to be killers as well as healers," says Koop.

Advocates of physician-assisted suicide say the fears of the disabled are exaggerated.

Faye Girsh of the Hemlock Society says making physician-assisted suicide legal "will bring it out of the darkness" and impose restrictions that would pre-

Australian suicide sanctioned by law

A woman suffering from a rare and painful skin cancer has become the second person in Australia's Northern Territory to commit euthanasia under a controversial law permitting doctor-assisted suicide.

Janet Mills, 52, died Thursday in Darwin, a coastal city in the Northern Territory, her doctor confirmed Sunday. Philip Nitschke said he helped Mills switch on computerized equipment that administered a lethal drug dose.

In 1995, the Northern Territory's legislature became the first in the world to legalize voluntary euthanasia. But churches and many doctors oppose doctor-assisted suicide, and Australia's Federal Parliament is considering a bill to overturn the law.

The Associated Press

vent abuse, such as requiring second opinions and establishing waiting periods.

"The right-to-die movement will never have the intention to eliminate vulnerable populations, including the disabled," says Girsh.

After arguments Wednesday, the court's opinion could come anytime before the end of the term in late June or early July.

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PRESERVATION

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