

Testimony of

# Ms. Kathryn Tucker

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## I. INTRODUCTION

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

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

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

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

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

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

Researchers have consistently found that experience in Oregon does not bear out concerns that physician-assistance 'would be disproportionately chosen by or forced on terminally ill patients who were poor, uneducated,

uninsured, or fearful of the financial consequences of their illness.'

## II. OVERVIEW OF OREGON LAW AND EXPERIENCE WITH IMPLEMENTATION:

### A. Passage and Challenges

The Oregon Death with Dignity Act ("Dignity Act") was passed in 1994 through the initiative process. Opponents of the Dignity Act have worked since then to overturn this law. First they sought relief from the Federal Government, urging the Drug Enforcement Administration ("DEA") to take action against Oregon physicians who acted in compliance with the law on the basis that such activity violates the Controlled Substances Act ("CSA").

The DEA initially opined that its agents could revoke the registrations of physicians who assisted in hastening deaths under the DIGNITY ACT. U.S. Attorney General Janet Reno, however, overruled this position, concluding that the CSA did not reach such conduct. Opponents then sought, in two successive sessions of Congress, to amend the CSA to expand its scope to reach the DIGNITY ACT. Both efforts failed in the face of strong opposition from the medical community founded on the concern that the proposed measures would exacerbate physicians' fears regarding the use of controlled substances in pain management.

A change in federal administration and philosophy led to a change in legal interpretation. The Bush Administration's first Attorney General, John Ashcroft, issued a Directive on November 6, 2001 (the "Ashcroft Directive"), advising that the Department of Justice had concluded that prescribing controlled substances under the DIGNITY ACT violated the CSA".

The Ashcroft Directive was challenged in federal court by the state of Oregon, an Oregon physician and pharmacist, and a group of terminally ill Oregonians, who asserted that it violated the CSA, the Administrative Procedure Act and the U.S. Constitution. The federal district court, the Ninth Circuit Court of Appeals, and the United States Supreme Court all concluded that the Directive exceeded the authority granted under the CSA, and a permanent injunction was entered. The Supreme Court held that the Attorney General did not have the authority to effect a "radical shift" in the balance of state-federal power as it pertains to the regulation of the practice of medicine. The Court reaffirmed the traditional state-federal balance of power in regulating the practice of medicine, specifically upholding Oregon's physician-assisted dying law as a legitimate regulation of medicine. By noting that General Ashcroft's view of physician-assisted dying was but "one reasonable understanding of medical practice," the Court made clear that Oregon's view also is reasonable.

### B. Implementation of the Oregon Law

The DIGNITY ACT establishes tightly controlled procedures under which competent, terminally ill adults who are under the care of an attending physician may obtain a prescription for medication to allow them to control the time, place, and manner of their own impending death. The attending physician must determine, among other things, that the patient is mentally competent, an Oregon resident, and confirm their diagnosis and prognosis. To qualify as "terminally ill" a person must have "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months."

The attending physician must also inform persons requesting such medication of their diagnosis and prognosis, the risks and probable results of taking the medication, and alternatives to taking their own lives, including, but not limited to, hospice care and pain relief. A consulting physician must confirm the attending physician's medical opinion.

Once a request from a qualifying patient has been properly documented and witnessed, and all waiting periods have expired, the attending physician may prescribe, but not administer, medication to enable the patient to end his or her life in a humane and dignified manner. The DIGNITY ACT immunizes physicians and pharmacists who act in compliance with its comprehensive procedures from civil or criminal sanctions, and any professional disciplinary actions based on that conduct.

The DIGNITY ACT also requires healthcare providers to file reports with the State documenting their actions ; thus, Oregon's experience with legal physician-assisted dying has been extensively documented and studied. To date, the Oregon Health Division and/or the Oregon Department of Human Service Office of Disease Prevention and Epidemiology have issued eight annual reports that present and evaluate the state's experience with the DIGNITY ACT. Related reports and articles have also been published in leading medical journals. These reports constitute the only actual source of reliable data regarding the experience of legal, regulated physician-assisted dying in America. These reports have shown the dire predictions of those initially opposed to the DIGNITY ACT to be baseless. The data clearly demonstrate that the option of physician-assisted dying has not been unwillingly forced upon those who are poor, uneducated, uninsured or otherwise disadvantaged. The Reports show the following:

- ? use of physician-assisted dying is strongly associated with a higher level of education; those with a baccalaureate degree or higher were 7.6 times more likely than those without a high school diploma to choose physician-assisted dying.

- ? ninety-nine percent of patients opting for physician-assisted dying during the DIGNITY ACT's first six years had some form of health insurance and eighty-six percent were enrolled in hospice care.

- ? use of physician-assisted dying is limited. During the first six years in which physician-assisted dying was a legal

option, a total of only 171 Oregonians chose it. The number of terminally ill adults choosing this option in 2003 represented only one-seventh of one percent--i.e., 0.0014 percent--of Oregonians who died that year.

Indeed, rather than posing a risk to patients or the medical profession, the DIGNITY ACT has galvanized significant improvements in the care of the dying in Oregon. These include:

? greatly increased enrollment by Oregon physicians in Continuing Education courses to improve their knowledge of the use of pain medications for the terminally ill, improving their ability to recognize depression and other psychiatric disorders, and more frequently referring their patients to hospice programs.

In sum, the available data demonstrate that making the option of assisted dying available, far from posing any hazard to patients or the practice of medicine, has galvanized improvements in end of life care, benefiting all terminally ill Oregonians.

The experience in Oregon reveals much about why dying patients choose to hasten impending death. In nearly all cases, multiple concerns contributed to the request. The patient's most frequently cited concerns include a decreasing ability to participate in activities that made life enjoyable, the loss of autonomy, and the loss of dignity.

A core argument made in opposition to legalizing the option of assisted dying contends that what terminally ill patients really need is good pain management and palliative care, not hastened death. These opponents contend that motivation to improve pain management will be undermined if assisted dying is an available option. Yet, as noted above, the Oregon experience has shown that legalization of assisted dying has galvanized efforts to improve pain management, and hospice enrollment in Oregon is stunningly high among patients who choose to make use of THE DIGNITY ACT. Terminally ill Oregonians do not choose assisted dying because they have untreated pain, quite the contrary; Oregonians have access to good pain and symptom management. Only the relatively few patients who find that the cumulative burden of their terminal illness is intolerable, and who persist in a desire to hasten impending death, go on to utilize THE DIGNITY ACT.

### III. OVERVIEW OF SUPPORT FOR THE OPTION OF PHYSICIAN AID IN DYING

Though Oregon is the only state to have yet legalized the option of physician aid in dying, support for the option is widespread nationwide.

? Harris poll, January 2002, found that sixty-five percent of respondents support legalization of the right to physician-assisted dying and sixty-one percent favored implementation of a version of the DIGNITY ACT in their own state.

? Another group of studies found that between sixty-three and ninety percent of people with a terminal illness support a right to physician-assisted dying and would like to have the option available to them.

? In California, surveys in March 2006 and March 2005 found that 70% of California residents support the idea that "incurably ill patients have the right to ask for and get life-ending medication." An assisted dying measure introduced in the California State Legislature in 2005 has garnered strong support.

? Support is found among persons of diverse religious faiths.

Support is also strong among physicians:

? A national survey conducted in March 2005 found that 57% of physicians believe it is ethical for a physician to assist a competent, dying patient hasten death.

? A 2001 survey published by the Journal of the American Medical Association found that fifty-one percent of responding physicians in Oregon supported the DIGNITY ACT and legalization of physician-assisted dying.

? A nationwide survey published in 2001 in the Journal of General Internal Medicine found that forty-five percent of responding physicians believed that physician-assisted suicide should be legal, whereas only thirty-four percent expressed views to the contrary.

? Mental health professionals recognize that dying patients can choose aid in dying and be fully mentally competent.

? A significant number of medical associations have decided to embrace a position of "studied neutrality" on the question of legalizing physician-assisted dying, recognizing the division within the medical community on the question.

### IV. THE BACK ALLEY, COVERT PRACTICE

Although legal only in Oregon, physicians throughout the country regularly receive requests for assistance in dying. Nearly thirty-percent of physicians responding to a 1998 New England Journal of Medicine survey stated that, since entering practice, they had received a request from patients to hasten death. Of those physicians who had received such a request, twenty percent had complied.

A survey of physicians in Washington revealed that twelve percent of had received a request to hasten death during the previous year, and twenty-four percent of the patients who requested medications to hasten death received them, notwithstanding the fact that Washington does not have a law in place like the DIGNITY ACT.

Patients who cannot find a physician willing to assist under existing law often act alone or with assistance from family members. Many people shared such stories in amicus briefs submitted to the Supreme Court in the Glucksberg, Quill and OR v. Gonzales cases. These stories detailed the suffering of loved ones who did not have access or authority to end their own lives. One woman told the story of her husband who had terminal cancer of the spine, lungs, and

lymphatic system. Unwilling to await death in a drugged state, her husband kissed his wife good-bye and shot himself in the front yard. "I wish I could have been with him at the end, but he said 'no, it will be messy.'"

Another woman detailed the death of her daughter who was dying of bone cancer. Despite the excruciating pain, her daughter feared for her mother's participation in ending her life. "I should be able to talk with my doctor and plan this, not ask my mom. Mom, what if you go to prison? What will happen to you?" Nonetheless, the woman assisted her daughter by giving her medication. "It was the ultimate act of love a mother could do for her suffering, dying child." When her daughter died, the woman was finally able to hug her daughter without hurting her. Many other such stories have been told: from loved-ones who helped patients die, to others who helplessly watched patients die and the resulting effects on the surviving family members.

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

#### V. CONCLUSION

In *Glucksberg* and *Quill* the Supreme Court recognized that Justice Brandeis's concept of the states as laboratories was particularly applicable to physician assisted dying. The Court's conclusion in those cases that the federal constitution does not bar states from prohibiting physician assisted suicide rested in large part on a reluctance to reach a premature constitutional judgment that would cut off the process of democratic decision making in the states. It is timely, prudent and humane for states to enact laws to empower terminally ill, mentally-competent adult citizens to control the timing and manner of their deaths by enabling them to obtain medications from their physician that could be self-administered to bring about a peaceful and humane death, subject to careful procedures. Passage of such laws would harm no one, and would benefit both the relatively few patients in extremis who would make use of them, and a great many more who would draw comfort from knowing this option is available should their dying process become intolerable to them.