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The Right to Die Speech 3/26/13

I was born in 1942 and raised as a Conservative Baptist Christian. In my late 20's, after considerable doubt and searching, I became a Unitarian Universalist Humanist. In 1974 I observed my father, Kenneth, die slowly, in great pain, and usually drugged to oblivion, from prostate Cancer spread to his bones. He once awoke enough to say my name, which made me feel that he wanted me to stop the horror of it all.

I attended Unitarian Universalist Seminary and worked in hospitals as a Student Chaplain where I observed people dying slowly and painfully of many kinds of Cancer, dementia, and other diseases. I cannot count the number of times that people said to me that modern medicine keeps a person alive long after they would have died naturally and that we treat our pets better than we treat people.

During the next 30 years while I worked full time as a Federal Labor Investigator, I visited many people who were dying the same way. Among them my wife Joyce lived seven years with cancer, and Chemotherapy, while the cancer traveled from her breast to her lungs, ovaries, bones, and other organs. The last full day of her life, in 1996, at age 53, she came awake enough to plead with me to take her home. They drugged her unconscious and the next day I went in with my son Brett, age 19, daughter Brita, age 16, and other family members, Minister and friends, to talk to her, whether she heard us or not, and to be with her while the doctors stopped the machines. She died within minutes after years of suffering.

I saw Carolyn, the younger of my two older sisters die in 2004 of Cancer of the lung and heart after radiation had burned her Esophagus so badly that she was unable to eat and had to be kept drugged unconscious while she was kept on Oxygen and machines to keep her alive.

In 2005 I watched my mother after years of dementia, afraid of little people, and terrible scenes in her mind, die slowly. Then I saw my oldest sister, Janice, dying in 2010 with the understanding that she would not be hooked up to machines, to keep her alive without hope of recovery. Her husband told the doctor, in the presence of her children,

and me, that she did not want to have a tracheotomy. The doctor would not take his word for it and stopped her pain medication so she could wake up when he asked her directly. She could only shake her head, "No." The doctor told me he was trained to keep people alive, not to let them die. Thankfully he honored her wishes and she died without more meaningless abuse.

Until the 20th Century, women, Jews, black, Asian and gay people did not have many of their Rights. Now they are more protected. Now it is time for those who are dying in horrible pain to be able to die with dignity.

In 1967 there was an unsuccessful Right to die bill in Florida. In 1980 Derek Humphrey founded the Hemlock Society to work on the issue of the Right to die with dignity. In 1987, Senator Frank Roberts of Oregon sponsored Legislation for the Right to die.

In 1990 the U.S, Supreme Court approved the Right of the State of Missouri to ask for decisive evidence of a patients request regarding artificial food and hydration and also approved a patients right to refuse medical treatment and to approve a health care proxy.

In 1991 there was a ballot measure in Washington State to allow mentally competent terminally ill patients to have physician assistance in dying. The ballot narrowly failed. Derek Humphrey, the founder of the Hemlock Society, published, "final Exit: the practicalities of self deliverance for the terminally ill."

In 1992 the California "Death with Dignity Act," narrowly failed. In 1993, "Compassion in Dying" was founded in Washington State.

In 1994 "Compassion in Dying" filed two Federal lawsuits asserting that mentally competent, terminally ill patients have a right by the U. S. Constitution for liberty, privacy and equal protection to choose aid in dying. The first case was filed in Washington State. That case was found in favor of Compassion in Dying. Washington State filed appeal to the 9th Circuit Court. The second case was filed in New York State.

Attorney Kathryn Tucker represented Compassion in both cases and became Legal Director for Compassion. Also in 1994, Oregon voters approve the right of dying patients, with Proper safeguards, to obtain a physicians prescription to end their lives in a humane and

dignified manner. Barbara Coombs Lee, President of Compassion, was the co-author of that law.

In 1996 The 9th Circuit Court of Appeals in the Washington State case, and the 2nd Court of Appeals in the New York State case, both found that the U.S. Constitution protects the choice of a competent, terminally ill patient to choose aid in dying. The States of Washington and New York filed for review by the U.S. Supreme Court.

In 1997 Compassion in Dying of Washington State, founded the national, “Compassion in Dying Federation,” expanding for National Advocacy and Support programs.

The Oregon law was challenged by the National Right to Life committee. It was held up by the courts and dismissed by the 9th Circuit. The Oregon Legislature put a measure on the ballot to rescind the law. It was defeated by 60% of the voters.

The U.S. Supreme Court declined to find on the issue of Constitutional Protection in the Washington State case, leaving open the possibility that they would do so in the future and referred the issue to the States. The Court found that a patient has a right to all the pain medication that they need, even if it advances the time of death.

The Hemlock Society established a Caring Friends Program. Representatives and Senators introduced the Lethal Drug protection Act to prohibit legal aid in dying. Hawaii, Vermont, and California considered enacting death with dignity laws. The Catholic Church, Right to Life, and disability advocacy groups funded opposition and defeated the State measures.

The Oregon Death With Dignity Act began implementation and, in 1997, a woman name Helen became the first person to take lethal medication.

In 1999 the U.S. House of Representatives passed the Pain Relief Promotion Act to criminalize aid in dying and nullify the Oregon law. In 2000 Oregon Senator Ron Wyden threatened filibuster and kept the law from reaching the Senate floor. In 2001 Attorney General John Ashcroft issued a directive effectively nullifying the Oregon Death With Dignity Act. Federal District Court Judge Robert E. Jones blocked the Ashcroft directive.

Compassion in Dying Legal Director Kathryn Tucker brought the first case in the Nation, in California, claiming that failure to treat pain adequately constitutes elder abuse, winning a 5 million dollar verdict establishing that failure to treat pain adequately can result in large financial losses for health care providers. Compassion presented legislation in California requiring that physicians receive continuing education in pain management.

By 2002, after five years of the Oregon law, 129 terminally ill patients had been allowed to die peacefully. A Federal Judge ruled against Ashcroft and rebuked the Federal government for attempting to stifle debate on assisted suicide.

In 2003 The Hemlock Society evolved to become End of Life Choices. In 2004 The Department of Justice appealed the lower Court decision against Ashcroft and the Federal Government. The 9th Circuit upheld the lower Court. Ashcroft appealed to the Supreme Court to allow the Federal government to displace State regulators in the legitimate use of medications.

In 2005 Compassion in Dying merged with End of life Choices to become Compassion and Choices. Barbara Coombs Lee became President and Kathryn Tucker became Legal Director. In 2006 American Medical Women's Association adopted a policy to support aid in dying. In 2006 Compassion and Choices gave testimony in support of California's Compassionate Choice Act, which failed, by a narrow margin.

In 2008 the American Public Health Association adopted a policy of language to discuss end of life choices. Compassion and Choices filed a suit in Montana arguing that Montana law protects a peaceful death with dignity. Washington State Psychological Association approved a policy regarding value neutral terminology regarding end of life choice.

American Medical Students' Association adopted a policy reiterating and broadening support of Aid in Dying.

Ten years of data from Oregon began to inform discussion about the impact of the legal aid-in-dying option. Washington Initiative 1000, modeled after Oregon's Death with Dignity Act, qualified for the November 2008 ballot. A bill developed by Compassion & Choices designed to ensure that terminally ill patients have access to information about a full range of end of life choices was accepted into

law and medicine, passed in California as AB 2747, the Right to Know End-of-Life Options Act. On September 30, 2008, Governor Schwarzenegger signed the Terminal Patients' Right to Know End-of-Life Options Act, AB 2747 (Berg-Levine).

The American Public Health Association adopted a position supporting death with dignity for terminally ill patients. On November 4, 2008, Washington voters overwhelmingly approved I-1000 59% to 41%. Washington is the second state to Legalize Aid in Dying! The Yes on I-1000 Campaign has moved patient's rights forward.

The Oregon experience shows that Aid-in- dying law benefits all people at the end of life. It provides comfort and control to the terminally ill and ends violent deaths. Montana District Court Judge Dorothy McCarter held in December 2008 that the Montana State Constitution protects peaceful death with dignity making Montana the third state to provide its residents with legal Aid in Dying. Compassion & Choices Legal Director Kathryn Tucker and Missoula litigator Mark S. Connell led the successful Baxter et al v. Montana case, filed October 2007.

On January 1, 2009 the Terminal Patients' Right to Know End-of-Life Options Act, AB 2747 (Berg-Levine) went into effect in California. Compassion & Choices called on the Obama Administration to repeal last-minute regulations allowing denial of medical services based on health care workers religious beliefs. Washington's Death with Dignity Act began implementation.

As the health insurance reform debate heated up in Washington and around the country, Compassion & Choices aggressively responded to a misinformation campaign launched by opponents of end-of-life choice to undermine a key provision of health insurance reform. Recent action and statements indicate the end-of-life consultation provision may survive in a final health care bill.

Compassion & Choices Legal Director Kathryn Tucker filed suit in Connecticut on behalf of two Connecticut physicians, Gary Blick and Ron Levine, asserting that the Connecticut statute, which makes it a crime to assist someone to "commit suicide" does not reach the conduct of a physician providing aid in dying.

Congressman Earl Blumenauer of Oregon stood with leaders of the House of Representatives as they unveiled House Resolution 3200, Section 1233, the Life Sustaining Treatment Preferences Act of 2009 that would provide coverage under the Medicare Program for consultations.

Senator Jay Rockefeller championed end-of-life care in his report to the Senate Finance Committee's health care reform legislation. Compassion & Choices continued work to assure end-of-life choice remains a key component of the final health insurance reform package.

Compassion & Choices hosted "Dignity & Choices, A Symposium on End-of-Life Advocacy" in Washington, D.C., Two days of discussion, exploration and study. Dignity & Choices provides an opportunity to promote principles and practices that focus on patients. Physicians, social workers, nurses, attorneys and advocates for end-of-life choice filled the National Press Club to hear aspects of end-of-life care rarely discussed and illuminate the way forward.

The Montana Supreme Court ruled in favor of the landmark case brought by Compassion & Choices (Baxter v. Montana) affirming that it is not against public policy of the state of Montana for a physician to provide aid in dying to a mentally competent, terminally ill individual.

In 2010, the Older Women's League devoted its 30th anniversary Mother's Day Report to end-of-life choices and hosted a Capitol Hill policy briefing on the issue. The report featured a piece, "Aid in Dying: A Matter of Elder Justice and Civil Rights," by Kathryn Tucker, Director of Legal Affairs for Compassion & Choices.

On June 2, Blick et al v. Connecticut was dismissed without reaching the merits, on sovereign immunity grounds, denying plaintiffs the opportunity to make their case to distinguish committing "suicide," from a mentally competent terminally ill patient ingesting medications to bring about a peaceful death.

New York passed the Palliative Care Information Act. The law, drafted by Compassion & Choices, and modeled after a similar measure in California, required healthcare workers to provide information and counseling on end-of-life options.

Compassion & Choices filed the groundbreaking lawsuit Hargett v. Vitas seeking accountability for the unnecessarily painful death of 43-year-old mother of three, Michelle Hargett-Beebee, who was never informed of the availability of palliative sedation. This is the first case in the nation to allege that failure to tell a patient about palliative sedation falls outside the standard of care.

In 2011 Legislative opponents introduced SB 116 in Montana, to nullify the Montana Supreme Court's landmark ruling in Baxter v. Montana, a case litigated by Compassion & Choices. The Montana Medical Association testified in official opposition to the measure. The Montana Senate Judiciary Committee declined to adopt this measure, preserving the option of aid in dying for Montanans.

A bill, amending Washington's Death with Dignity Act, SB 5378, failed to pass out of committee, in response to Compassion & Choices proactive efforts and voter support. SB5378 would have amended the section of DWDA specifying deaths under the Act do not constitute "suicide."

Compassion & Choices launches successful public campaign throughout Oregon to defeat HB 2016, a bill requiring all terminally ill patients who request aid in dying to undergo psychiatric evaluation. The Oregon House HealthCare Committee holds no hearing or work session on HB 2016.

I have testified at a Press Conference and to reporters at a Legislative Committee at the State of Connecticut Capitol on the Right to die. It will be months before we have a decision by the Connecticut Legislature but we will never quit.

I believe strongly in modern medicine, which has given all of us longer, healthier, happier lives, but when a person is dying and says enough is enough we should honor their wishes. The law protects everyone to live as long as they can with no obstacles. We put down our pets when only death can help. We don't want this lack of Choice happen to you and your loved ones, who are now well enough to make their own decisions. We want to give the few, who have no choice but to die, the rights they should have and the relief that they need.