HOWARD BALL

AT LIBERTY TO DIE

The Battle for Death with Dignity in America



NEW YORK UNIVERSITY PRESS New York and London www.nyupress.org

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Library of Congress Cataloging-in-Publication Data Ball, Howard, 1937-

At liberty to die : the battle for death with dignity in America / Howard Ball. p. cm.

Includes bibliographical references and index.

ISBN 978-0-8147-9104-2 (cl : alk. paper)

ISBN 978-0-8147-6975-1 (ebook)

ISBN 978-0-8147-4527-4 (ebook)

- 1. Right to die Law and legislation United States.
- 2. Assisted suicide Law and legislation United States.
- 3. Euthanasia Law and legislation United States. I. Title.

KF3827.E87B36 2012

344.7304'197 — dc23 2011052258

New York University Press books are printed on acid-free paper, and their binding materials are chosen for strength and durability. We strive to use environmentally responsible suppliers and materials to the greatest extent possible in publishing our books.

Manufactured in the United States of America

10 9 8 7 6 5 4 3 2 1

AT LIBERTY TO DIE

DEDICATED TO THE MEMORY OF A GOOD FRIEND,

DON BEXTERMUELLER.

He loved his Linda and his mules. He died in Hospice.

ACKNOWLEDGMENTS

During research and writing of this book, I have had the great pleasure of meeting with a variety of medical practitioners across the nation. They include pathologists at the University of Vermont's Medical School and the Dartmouth-Hitchcock Medical School. Their discussions with me and my students regarding how humans die in this new century was of great help to me in gaining insight into this key issue. In addition, I have had the insights of many doctors and nurses, both pro and con on the issue of death with dignity, in Vermont, Arizona, Utah, North Carolina, Montana, and Oregon about physician-assisted death (PAD). I gratefully thank the Center for Disease Control and Prevention for basic data on American mortality.

While teaching at the University of Utah in the 1980s, I had the pleasure of discussing the general issue with a preeminent scholar, Margaret Battin, a professor in the Philosophy Department. She has been thinking and writing about a person's liberty to die with dignity for decades and has been in the forefront of thinkers whose ongoing task is to teach about the liberty one has of dying with dignity.

During the late fall 2008, en route to Arizona, I had a heart attack and triple bypass surgery in North Carolina. I had excellent care by the cardiac care team at Forsyth Medical Center in Winston-Salem, led by my "plumber," Dr. David Duncan. While recovering, I had insightful discussions about the medicalization of death with a variety of personnel, including the members of the hospital's palliative care center. They are in the forefront of compassionately caring for the terminally ill.

Thanks also to my friend and companion for nearly fifty years, my wife, Carol. Nor can I forget the rest of my family, Susan, Sheryl, Jay, Lila, Nate, Melissa, Tim, Sophie, Stormin' Norman, Candyman, Harry, Charlie, and Cooper. I love all of you.

Finally I gratefully acknowledge my editor, Deborah Gershenowitz, for her work on my behalf from the very beginning of this project. She is a gem, and it was my good fortune to work with her for the past four years.

None of these men and women is responsible for any errors in the book. I take responsibility for all of them.

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INTRODUCTION

Dudley Clendinen is a sixty-six-year-old author and columnist dying of amyotrophic lateral sclerosis (ALS, known as Lou Gehrig's disease). In a recent essay, he discussed his existential situation.¹ There is no meaningful treatment for ALS nor is there a cure. "Lingering would be a colossal waste of love and money. I'd rather die," he wrote. Although leaving his daughter "is the one thing I hate. But all I can do is to give her a daddy who was vital to the end, and knew when to leave. . . . When I can't tie my bow tie, tell a funny story, walk my dog, kiss someone special—I'll know that life is over. It's time to be gone."²

The central thesis of the book is that the liberty found in the U.S. Constitution's Fifth and Fourteenth "Due Process" Amendments extends to Dudley Clendinen and other terminally ill competent persons' right to choose to die with dignity—with the passive assistance of a physician—rather than live in great pain or live a quality-less life. While Adderal judges and most state legislatures have not yet moved to accept this view, the book will show that there has already been some modest movement of that direction, one that presently allows terminally ill patients to die will be assistance of a physician in two states, Oregon and Washington Recently Montands Supreme Court, talled that the state constitution does not prohibit physician-assisted death (PAD) but, to date, there has been little legislative action to establish the necessary guidelines for medical practitioners to follow when ministering to their terminally ill patients who wish to die on their own terms.

However, there is an unusual consequence if there is no further movement toward either judicial expansion of the meaning of liberty or the passing of laws enabling terminally ill patients to die with the assistance of a doctor: terminally ill people crossing state lines to enter those states that allow such medical assistance. It is these persons—strong-willed, competent and dying adults who want to die with dignity when faced with a terminal illness—who are the eight-hundred-pound gorillas in this book.

This transient activity is not a hypothetical situation. It is presently occurring throughout the world and goes by a number of names: the "Switzerland

syndrome," "Death tourists," "Suicide Tourists": these are men and women who transplant themselves to obtain medical assistance in taking their lives because of terminal disease that either leaves them in great pain or robs them of a decent quality of life.

In America, there is the specter of some terminally ill people—"Oregon Transplants" one Arizona lawyer labeled them⁴—in America traveling to Oregon, Washington, and now Montana in order to obtain passive physician assistance in dying.⁵ Hospice and palliative care developments have lessened this kind of transient movement to die a good death in a state where that is possible. In addition, for decades physicians have used the "double effect" practice to assist their dying patients. (This protocol allows a doctor to give painkilling medications to a terminally ill patient to relieve pain, with the possibility that the treatment will indirectly hasten the patient's death.)

A small number of Americans will still travel in order to seek out a place to die with some dignity. This possibility parallels earlier actions Americans once took in order to obtain an abortion (which was illegal in their home state)⁶ or to marry because of their state's prohibitions against marriage of persons of different races or of the same gender.⁷

For more than a century, the U.S. Supreme Court's decisions have acknowledged that a person has the constitutionally protected liberty to travel from state to state. The first case decided by the Court was *Crandell v Nevada*, 1868,8 where the Justices unanimously struck down a Nevada law that levied a \$1 tax on persons leaving the state by public transportation. The right to travel from state to state was a right of national "citizenship" found in the "privileges and immunities" clause of the Fourteenth Amendment. And in 1941 another unanimous Court decision invalidated a California statute that sought to keep nonresidential indigent "Oakies" out of the state.9

Furthermore, because of legal and medical events that have taken place in America since the 1970s, described in this book, there has developed—in society and in the medical community—a growing awareness of the needs, choices, and rights of dying patients. There is also a greater understanding of the dying process and a corresponding ease when talking about death and dying that did not exist until the last decades of the twentieth century.

Americans live much longer now than a century ago. The average life expectancy for a person born in 1900 was forty-seven years; for a person born in 2010, it is more than seventy-eight years. Seniors are not only living longer

but most are dying ever so slowly. For many, their families see them in great pain. A friend of mine told me that her dying father "dropped from around 250 pounds . . . down to about 80 in the time it took him to die. All I recognized the MONTH before he died . . . were his eyes. It was a terribly gruesome and undignified death."

A majority of Americans now believe that a terminally ill person has the right to determine how her life will end. Public opinion polls over the years indicate that a growing number of Americans support a person's right to choose to die with the assistance of a physician. A typical poll result: a 2005 Pew Research Center Survey noted that 84 percent of those polled approved of patients being able to decide whether to be kept alive through medical treatment or choosing to die with dignity—with only 10 percent opposed. However, religious, medical, political, and ideological communities have, to date, successfully countered the public's positive view of this personal liberty. They have defeated most efforts to transfer this idea into legislation.

There is, also, a significant change in the way the medical community views and treats pain. There is a growing acceptance of the importance of minimizing pain by all means necessary—even if this effort leads to the death of the individual. In 1974, there was just one palliative care hospice facility in America providing a handful of terminally ill cancer patients relief from excruciating pain. In 2010, nearly five thousand hospice-palliative care programs in all fifty states and American territories are caring for more than one million terminally ill patients. In less than forty years, America has moved from a minimum number of patients treated and dying in hospices to, in 2009, nearly 42 percent of all deaths (1.2 million) occurring in a hospice program. Between 2000 and 2008, the number of hospital-palliative care programs grew exponentially. While there has been significant change, more than half of American terminally ill patients still die in hospitals, some in great pain, without palliative care.

For all those who have experienced the way most Americans die in the twenty-first century, the solution to the horror of a delayed degenerative disease such as cancer is death with dignity: palliative care, hospice, and, for a few, physician-assisted death." It is, Margaret Battin argued, *not suicide* but the "least worst" death. An eighty-six-year old man in Oregon, diagnosed with terminal COPD, reflected Battin's thoughts when he said to a reporter: "I'm not suicidal. I'm sane. When the time comes, I'm going to swallow that

bottle of Lethe¹⁴ and say goodbye."¹⁵ As changes in American attitudes toward death occur, it is increasingly important to consider how the meaning of liberty in the U.S. Constitution relates to one's personal choice regarding death.

For nearly a half century, there has been an insistent constitutional argument made by individuals whose personal choice to die, by receiving a prescription for lethal medications, state law prohibited. There is a fundamental liberty interest, they claimed, found in the U.S. Constitution's "Due Process" Clause. 16 It enables a person to make personal, intimate, and ultimate choices without interference by government.

For some dying persons, liberty is their right to choose death over life. They claim that the right to die with dignity is a constitutionally protected choice a person has under both the common law and the Constitution. This concept of liberty as personal privacy and autonomy saw its constitutional life begin in 1965 in a marital privacy case that came to the U.S. Supreme Court from Connecticut. In 1965, in *Griswold v Connecticut*,¹⁷ a seven-person U.S. Supreme Court majority ruled that the liberty concept in the U.S. Constitution extended to a married couple's *right to marital privacy* in the bedroom.

There is, the lawyers argued, a "fundamental personal right of privacy" possessed by married couples. The challenged Connecticut law, an 1879 statute that made it a crime for any person to use any drug, article, or instrument to prevent conception, was declared unconstitutional. Justice William O. Douglas for the Court majority, argued that the Connecticut law interfered with the right of privacy found in the "penumbras" of the Constitution's Bill of Rights, specifically the First, Third, Fourth, Fifth, and Ninth Amendments.

Justice Arthur Goldberg's concurring opinion in *Griswold*, joined by Justice William J. Brennan and Chief Justice Earl Warren, featured a much more expansive definition of a person's liberty interests found in the nation's constitutional history: "Liberty protects those personal rights that are fundamental, and is not confined to the specific terms of the Bill of Rights."

For Justice Goldberg, judges and justices adjudicating a controversy between an individual's use of a "fundamental right" and a state law prohibiting such an action had to determine whether that claimed right was "so rooted in the traditions and conscience of our people so as to be ranked as fundamental [in our constitutional law]."¹⁹

Justice John M. Harlan II, joined by Justice Byron White, refused to accept either constitutional justification offered by his colleagues. Instead, he

argued in his concurring opinion, the Due Process Clause and specifically its liberty component "stands on its own bottom." For Harlan, the Connecticut statute violated basic historical, cultural, and legal principles "implicit in the concept of ordered liberty."²⁰

This "right" of marital privacy—the right to choose to use or not to use a contraceptive—until *Griswold* was not specifically found in the language of the Constitution. The majority, however, based on a trio of differing legal arguments written by Douglas ("penumbras"), Goldberg ("fundamental rights rooted in America's traditions"), and Harlan ("due process"), concluded that the state statute was unconstitutional.

The two dissenters, Justice Hugo L. Black and Justice Potter Stewart, argued that the statute was a nineteenth-century anachronism; it was essentially "a silly law." However, they concluded that it did *not* infringe upon a fundamental and enumerated constitutional right. Unless there was a specific, constitutionally authorized liberty or right infringed by a state law, even an admittedly "silly" law is constitutional. Their basic fear: "Use of any such broad, unbounded judicial authority [seen in the three majority and concurring opinions] would make of this Court's members a day-to-day constitutional convention." Interestingly, their understanding of judicial constraint in constitutional interpretation became, in the 1980s, the majority's position. It remains the dominant view of the Court majority today.

The *Griswold* decision, despite its different interpretations and understandings of the U.S. Constitution's liberty clause, was a watershed opinion regarding a person's right to choose to act in certain ways so long as the action did not injure others. All competent persons have a self-determined liberty to make choices they believe will benefit them.

A few years later *Griswold* was followed by another important decision that expanded upon the marital privacy principle. In 1972 *Eisenstadt v Baird* was decided by a seven-person U.S. Supreme Court.²² (Justices Black and Harlan retired in September 1971 and their replacements, Justices William Rehnquist and Lewis Powell, had not yet taken their seats on the Court.)

By a 6:1 vote,²³ in an opinion written by Justice William J. Brennan, the Court majority ruled that a Massachusetts law banning the distribution of contraceptives to *unmarried* persons was unconstitutional. In an expansion of *Griswold*, Justice Brennan concluded that "If the right of privacy means anything, it is the right of an *individual*, married or single, to be free from

unwarranted governmental interference into matters so fundamentally affecting a person as the decision whether to bear or beget a child."²⁴

The following year, the U.S. Supreme Court heard *Roe v Wade*,²⁵ the case that determined whether and under what conditions a woman could choose to have an abortion. By a 7:2 vote, with Associate Justices William Rehnquist and Byron White in dissent, Justice Harry A. Blackmun, for the majority, concluded that the challenged state statutes from Texas and from Georgia, which prohibited abortion, were unconstitutional on the ground that they violated a woman's right of privacy.

A woman has a liberty interest in determining the fate of the fetus she was carrying, Blackmun wrote. Although the right to an abortion was a right not specifically found in the Constitution, nevertheless the majority believed that a woman's liberty extended to her right of privacy to choose or not to choose to have an abortion.

Between 1965 and 1973, then, U.S. Supreme Court majorities laid down some very fundamental but, in the minds of its conservative critics, extraconstitutional principles regarding a person's right to choose in very personal, very private, very intimate circumstances: marital relations, sexual relations, and the right to have an abortion. For all those who believed that liberty extended to the right of a competent terminally ill adult to die with the assistance of a physician, these opinions were very encouraging ones. When these terminally ill men and women became plaintiffs and went into court to argue that they had a constitutional right to end their lives, these earlier cases were used as precedent for their position.

These pre-1973 decisions are the constitutional arguments that plaintiffs have made from the very first case brought into a court that challenged a state law which interfered with the decision to receive physician assistance in choosing to hasten death rather than continue life in a vegetative state, or life in constant pain, or life without dignity. They were the stepping-stones to litigation regarding the most profound personal decision a person can make—dying.

Those who defend the right to die with dignity insist that, like the privacy right, the right to die with dignity should fall under the protective mantle of the liberty found in the Constitution. They argue that a terminally ill person has a fundamental liberty to choose to die with the assistance of a physician. There is no difference between the liberty a woman has to have an abortion

and the liberty a competent terminally ill patient has to die under the person's own terms.

This book, in part, focuses on the legal and constitutional arguments and debates, in state and federal courts, and in the U.S. Supreme Court, regarding the argument that a dying person has a right to choose to die with a physician's assistance. Those seeking to expand the meaning of liberty contend that a state law barring physicians from providing that patient with a prescription for the necessary lethal drugs violates the person's liberty protected by the Due Process Clause.

By the mid-1970s, the first of the end-of-life cases came into state courts involving non-competent patients. In 1990, another set of political, ethical, and legal questions arose in state and federal courts. Can a competent terminally ill patient, suffering from a crippling, and at-times-painful illness, request a prescription for lethal drugs from a medical practitioner that would allow that patient to die with dignity? As the book shows, there were efforts in many states to draft legislation that would allow physician-assisted death of terminally ill patients. These battles were political, ideological, and religious ones, which for the most part led to political defeat for pro-PAD advocates.

There has always been in America the freedom to travel unimpeded to seek a better life. The prospect—in the twenty-first century—of dying persons traveling to a state that offers them the liberty to choose a good death necessitates telling the story of the constitutional history and the controversial debates—beginning in the 1970s—regarding a person's constitutional liberty to choose to die with dignity.

At the heart of this American story is a competent person's right of freedom of choice, a freedom over one's body that allows a person to die with the help of a doctor. It is a story that involves legal disputes regarding termination of life support for incompetent patients, medical arguments that start with the notion that a doctor must do no harm to the patient, and political battles over the meaning of liberty in the Constitution. One general consequence of these clashes of ideas over the past four decades is that there has been significant change in Americans' attitudes and beliefs about death and dying. Public perceptions of this controversial subject are far ahead of the views of federal and most state judges, and much more open to legislative change to reflect these attitudes than are the political leaders in the legislature and in executive mansions.

The story begins in chapter I with an examination of the "Medicalization" of death phenomenon that emerged during the twentieth century. This reality has led some people to seek out a merciful way to end their lives with the assistance of a physician. Over the past century, the nature of how we die has changed considerably. Science has discovered many ways to prolong a person's life. In so doing, it has created new problems associated with living too long. Many terminally ill patients are in great pain and are unable to live the life they had before the illness.

The end-of-life debates began in America with legal cases that addressed the fate of incompetent patients in a permanent vegetative state. Chapters 2 and 3, examine these contentious debates. Competent persons have the freedom to choose to refuse or to discontinue life-sustaining medical treatment. What about the incompetent patient? Three watershed cases—Quinlan, Cruzan, and Schiavo—raise and answer important constitutional, medical, religious, and political questions associated with the right of personal privacy and the constitutional liberty found in the Fifth and Fourteenth Amendments. More importantly, these cases have forced Americans to confront the reality of end-of-life problems that all must face.

The cases (1975–1990) that opened the controversial right-to-die legal, medical, and ethical debates raised the question of whether withholding or withdrawing of life support mechanisms from *incompetent* and *incapacitated* persons in a Permanent Vegetative State (PVS)²⁶ can take place without civil or criminal liability facing those who act to remove the life support systems from such patients.

In the *In Re Quinlan* (1976); the *Cruzan* (1990), and the *Schiavo* (1997–2005) litigation, state and federal courts for the very first time reviewed the facts and the law and the medical ethics issues in order to determine whether and under what conditions life support could be withheld or withdrawn from an incompetent patient. In *Quinlan*, the New Jersey Supreme Court based its ruling on the 1965–1973 right to personal privacy arguments presented by U.S. Supreme Court majorities. Drawing upon the decisions of that Court, especially *Roe v Wade*, the state court concluded that the life of a PVS patient could be ended by withdrawing life support.

By *Cruzan*, in 1990, the U.S. Supreme Court accepted the Missouri state standard for withdrawing life support systems: There must be shown "clear and convincing evidence" that the PVS patient, *when competent*, indicated—

verbally or by an advanced directive—that he or she did not want to be kept alive by machines if there was no quality of life possible. Moreover, the Court said that both the common law and the U.S. Constitution allow a *competent* patient to instruct medical professionals to remove life support systems so that the patient could die.

Terri Schiavo's case began when she was diagnosed as PVS by her doctors in 1990. Eight years later her husband, claiming that he was following her verbal instructions before her cardiac arrest, asked for a court order to have the hydration and nutrition tubes removed. However, Terri's parents disagreed with him and petitioned the courts to continue to keep their daughter on life support.

These battles, in the Florida courts, and in the state's executive and legislative branches, went on for seven years. By the time the international spectacle ended in March 2005, state courts, ²⁷ federal courts, the U.S. Congress, and President George W. Bush²⁸ were enmeshed in the exploited tragedy of an incompetent patient who had been in PVS since 1990. In the end, Terri Schiavo's life support tube was removed, and she died on March 30, 2005—nine days after President Bush signed Terri's law, which momentarily prevented removal of her life-sustaining tube.

Chapter 4 takes the story to its next plateau, moving from a general awareness of the end-of-life choices for caregivers of incompetent patients to focus on the public debates that addressed the question of whether a terminally ill competent patient who wants a "good death" has the constitutionally guaranteed liberty to achieve his or her goal. This issue became very visible due, in part, to the actions of Dr. Jack Kevorkian. His medical actions—beginning in 1990—brought into sharp focus the dilemma of persons suffering from illness and who wanted to die. Although the medical community and others condemned Kevorkian's aggressive actions to help patients die—many of them not suffering from a terminal illness—they opened the door to the next set of questions regarding the fate of competent patients. One major problem that faced these terminally ill competent patients was that the medical community, as a matter of principle and policy, was opposed to passive assistance by doctors to enable these dying patients to take their own lives.

Throughout the 1990s, grassroot efforts to pass death with dignity legislation came into existence, and there were pitched battles and highly emotional debates surrounding the rightness of such legislation. Very critical to these

discussions was the constitutional question regarding the scope of the liberty clause in the Constitution. Was the liberty, found in the Fifth and Fourteenth Amendments of the Constitution, as interpreted by the federal courts, a fundamental right that extended to a person's choice to end life with the help of a physician?

The U.S. Supreme Court in 1997 entered the discussions because of legal actions taken by PAD proponents—a few doctors joined with their terminally ill patients—in the federal courts. The Court concluded that the liberty sought by the plaintiffs was not a fundamental one. The liberty concept does not extend to a person's right to seek medical assistance in taking one's life. Its conclusions did not satisfy those who argued for the constitutional right to die. However, these decisions continued the discussion of the basic question: does liberty mean that a terminally ill competent person has the constitutional right to choose to die with dignity—with the assistance of a physician—rather than live in great pain or live a quality-less life?

Chapter 5 examines the alternative strategy of the PAD advocates: passing legislation that allows PAD. The chapter examines and analyzes the battles in the states over whether physician assistance in dying would become law. Nearly two dozen states, beginning in 1990, experienced intense political battles regarding PAD legislation. Over the course of two decades, most political battles led to the defeat of PAD legislation.

There were, however, two successes in the battles to pass legislation. Chapter 6 examines these political and legal battles. Oregon became the first state to pass a death-with-dignity law in 1994, although it was litigated in state courts until 1997. Additionally, at the federal level President George W. Bush's U.S. Justice Department attempted to invalidate the bill in 2001. The effort failed when, in 2005, the U.S. Supreme Court, invalidated the administration's strategy. Oregon's success was replicated by its neighbor, Washington State, in 2008. In addition, in 2009 the Montana Supreme Court interpreted the state constitution in a way that allows medical practitioners to provide terminally ill patients with prescriptions so that they may end their lives on their own terms. This chapter discusses these breakthroughs and whether they will impact the future of the death-with-dignity movement.

Are we at the end of the death-with-dignity story? This is the essential question raised in chapter 7. Americans at this moment have the freedom of movement, accompanied by their right to decide for themselves how they

want to live or die, and the liberty to choose to die in Oregon, in Washington, or in Montana. They will move if they feel that is the only way for them to go as they face their life's end.

Unless, of course, future interpretations of the Constitution by federal judges allow the terminally ill patient to use the liberty provided to all in the U.S. Constitution to seek out physician assistance in dying without becoming "Oregon transplants." This end-of-life drama will continue because in the federal court system significant changes in the makeup of U.S. Supreme Court personnel regularly occur. With new Justices deciding cases, there is the probability of new ways of interpreting the liberty clause in the Constitution. The PAD issue will continue to percolate in the state and federal courts because more and more people are succumbing to those chronic end-of-life illnesses (chiefly cancer and heart failure).

Unless there is continued expansion of the hospice and palliative care program in America, the death-with-dignity movement will continue to champion legislative changes in state law. (In 2010 nearly 60 percent of patients who died in America—2,450,000—did not have the vital assistance of palliative care professionals to make their final days less stressful and less painful.)

The right-to-die issue will continue to roil in controversy because it, like the right to an abortion, confronts the very essential beliefs of "sanctity of life" proponents. Religious groups, especially the Roman Catholic Church, continue to seek ways to ban abortion ever since *Roe v Wade* came down in 1973. They and other groups representing disabled persons and other Americans have fought to block PAD legislation since the 1970s and will continue to do so in the future.

Will more states pass death-with-dignity legislation similar to the existing legislative and legal decisions in Oregon, Washington, and Montana? Will federal judges, especially the Justices on the U.S. Supreme Court, enlarge the scope of liberty in the U.S. Constitution? Will palliative care and hospice programs continue to grow in the effort to deal mercifully with the dying patient's final days? These answers will probably be forthcoming in this decade. The book's final chapter examines these options and speculates about their success.