



Whose Agenda Is It Anyway?

As John Ashcroft took leave of his post at U.S. Attorney General, he fired a parting shot at Oregon's aid-in-dying law. He filed a petition with the U.S. Supreme Court, asking the justices to hear an appeal of *Oregon v. Ashcroft*.

By doing so, he signaled that opposition to Oregon's way of empowering patients at the end of life runs deeper than his single post. It indicates that religious conservatives at all levels of the administration are likely to continue the battle against Oregon and against aid-in-dying for years to come. Driven by a conservative religious agenda, virulent attacks seem out of step with traditional Republican values of self-determination, restraint of government interference, states' rights and personal responsibility.

"The U.S. Supreme Court has already written that aid in dying is a matter for individual states to decide. If the court respects its own precedent, it will deny Ashcroft's appeal," said Barbara Coombs Lee, president of Compassion and a chief petitioner of Oregon's unique law. "Even after three court victories, Compassion must once again marshal resources to oppose the Department of Justice and keep aid-in-dying available."



Ashcroft opened his attack on Oregon patients and their doctors on November 6, 2001. His directive attempted to reverse the legal analysis of his predecessor, Janet Reno, and instruct the Drug Enforcement Administration to prosecute physicians for prescribing life-ending medication to terminally ill, mentally competent Oregonians.

Compassion in Dying's legal team has represented 14 patient plaintiffs during the three-year court battle. Once again Compassion will muster the legal muscle necessary to ask the Supreme Court to reject the Ashcroft petition. We are cautiously hopeful the highest court in the land will decline to hear this case. We must bring all our dedication and available resources to the battle to preserve excellent care and the choice of a peaceful and humane death at the end of life.

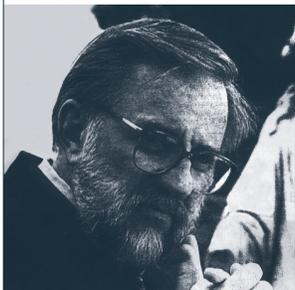
Repeated polls indicate most people of every faith and political persuasion favor choice at the end of life. Yet religious conservatives repeatedly seek to impose a narrow, doctrinaire view of morality on everyone throughout the nation. We vow to continue the struggle to realize the goals of individual autonomy at life's end even though the balance of power in Washington clearly rests with religious conservatives who pursue a vigorous agenda of change for our nation.

Aid-in-dying is only one battleground where freedom of conscience is under attack. But because everyone will one day face end-of-life decisions, it is a battleground of enormous importance to us all.

"Our lives begin to end the day we become silent about things that matter." — Martin Luther King Jr.

Connections

Victory Through the Courts



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Compassion of Oregon Gets Going



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Congress Determined to Overturn Oregon Law



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HCFA Rules Patients Must Receive Notice on Pain Care



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Senate Bill to Nullify Death With Dignity Act



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In Congress Nickles Pushes, Wyden Defends



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Doctor Found Reckless for Not Relieving Pain



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Compassion Fights Ashcroft in Court



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Commemorating Five Years of Comfort & Choice



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Oregon Law Survives Ashcroft Attack



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Judges Veer Off On Procedure Questions



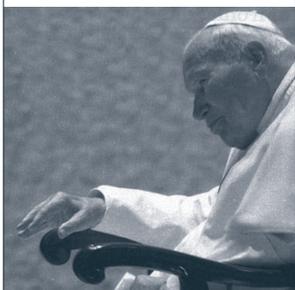
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Compassion Protests Unwanted Heroics



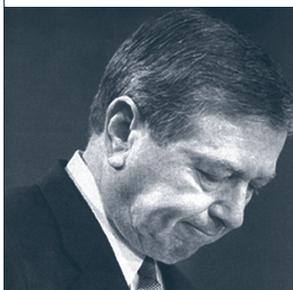
Connections

Vatican Decree Disrupts Advance Directives



Connections

Ashcroft's Third Strike Against Aid-In-Dying



10 years of Connections

This is the final edition of *Connections*. The unification of Compassion In Dying and End-of-Life Choices will bring a new magazine. Look for the new *Compassion & Choices* magazine this Spring.

10 years of history to build on

A Social Movement Whose Time Has Come

Early in 1993, at the peak of the AIDS epidemic, a small group of dedicated individuals witnessed too many violent, lonely and agonized deaths. They vowed to make a difference and founded Compassion In Dying in Seattle. Since 1993, we have counseled thousands of mentally competent, terminally ill adults about aid-in-dying and fought for its legalization.

When the Oregon aid-in-dying law took effect in 1997, Compassion had four years of experience bringing choice to comprehensive end-of-life care. Under Compassion's stewardship, Oregon's law has been implemented carefully and responsibly. Errors and complications opponents feared have not materialized. More importantly, choice at the end-of-life has empowered dying patients and brought measurable improvements in palliative care. The Oregon experience with assisted dying stands as a model for the nation.

Eleven years later, Compassion has built a national reputation in client services, legal advocacy and public education that is a source of pride. Compassion's work at the bedside, in courtrooms, legislatures and arenas of public dialogue has redefined care, choice, dignity and control at life's end.

Since January 2004, representatives from the board of directors of Compassion In Dying and End-of-Life Choices have engaged in historic dialogue to explore unification of the two organizations for the purpose of raising the voice and impact of the movement for end-of-life choice. On October 29, 2004,

Compassion & Choices became a unified organization.

The core values of Compassion & Choices come from our experience at the bedside of the people we help. We respect their choice. We protect their autonomy. We hold their confidentiality. We use these core values as a compass pointing toward our true goal.

We are clearly a social movement whose time has come. With unification our movement has hit its stride. Your generous support will help realize the last human right; that every person has access to excellent care and the choice of a peaceful and humane death.



New Compassion & Choices Board: (Standing) Florent Morellet, E. James Lieberman, MD, Barbara Coombs Lee, PA, FNP, JD (ex-officio), Marsha Temple (ex-officio), B. Kirk Robinson and Susan J. Dunshee (Seated) Prof. Sylvia A. Law, JD, Chris Loker, Paul Spiers, PhD, Mary Hoagland, JD and Robert V. Brody, MD

About Compassion...

Compassion assists the terminally ill and their families, providing counseling, advocacy, legal action and legislative reform nationwide. In Oregon and throughout the nation, Compassion helps the terminally ill obtain excellent end-of-life care and die peacefully. Compassion is a national non-profit organization, founded in 1993, and headquartered in Portland, Oregon.



OUR CALIFORNIA ASSISTED DYING BILL

“Two well-respected California assemblymembers, Lloyd Levine of Van Nuys and Patty Berg of Santa Rosa, have notified their colleagues that they intend to introduce an aid-in-dying bill fashioned after Oregon’s proven model next year. They have studied the questions, pro and con, carefully and concluded that Californians facing prolonged deterioration toward inevitable death deserve the right to die in a time and manner of their choosing.”

—Barbara Coombs Lee



Patty Berg
Assemblymember,
Committee on Aging
and Long-Term Care



Lloyd E. Levine
Assemblymember,
Majority Whip

To promote our pending legislation we need your personal story about a good or bad death in California. We need stories and storytellers in every assembly district in California. We are looking for first person stories to demonstrate that end-of-life care without assisted dying is inadequate. The best stories:

- Describe a person who wanted assistance with dying but either was afraid to ask their physician, or was rebuffed when they raised the subject.
- Describe a person who was unwilling to submit to the final ravages of their disease and took their life violently or prematurely, while they could still act alone.
- Describe a person who explored their options, such as stopping eating and drinking or stopping medical therapy.
- Describe a person who wanted to die with their senses intact, but who had to be sedated to unconsciousness to control pain or other symptoms.
- Describe a person who obtained life-ending medications through covert, surreptitious means. This story is compelling whether or not the patient ever took the medication to die. The story may describe the comfort the patient received in obtaining control over the dying process and having an escape if suffering became unbearable.

Contact Claire Simons at Compassion if you are willing to tell your story to your assemblymember: cs@compassionindying.org or **503.221.9556**



Photo by Mark Mann, Vassar, The Alumnae Quarterly

On My Mind

Barbara Coombs Lee, President

Most of us in the Compassion family are struggling with grief and discouragement over the election results. We do know our goals of care and choice at the end of life cross party lines. And we draw strength from the moderate, pro-choice Republicans in our camp.

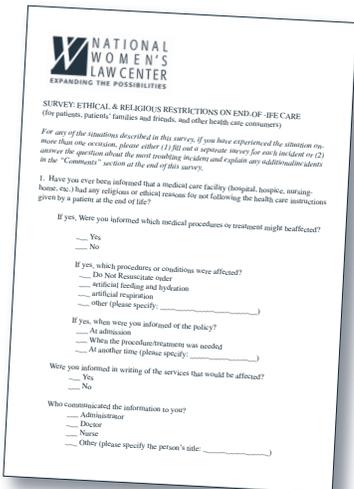
But the fact is this administration has done everything in its power to turn back our advances in Oregon, scare doctors and patients alike and return assisted dying to a dark, shameful, covert place. Now we face four more years of power for those who say our mission affronts God. The people in power would impose their beliefs about how to die, and how to live, on us all.

This week the master storyteller Clarissa Pinkola Estes entreated her friends not to lose heart, but to put their faith in small acts of kindness and courage. "Ours is not the task of fixing the entire world all at once," she wrote, "but of

stretching out to mend the part of the world that is within our reach." She stressed that we cannot know which acts or by whom will tip the scale toward enduring goodness. Our job is only to do our part, to bring the best of ourselves to all we do, and to respect and care for one another in a multitude of diverse ways.

One thing is clear. Our movement has honed a leading edge in the battle for human dignity and individual freedom. End-of-life choice marks one of the great arenas where autonomous decision-making battles dogma. In this arena David might slay Goliath and the world would feel a shift. We have already kept John Ashcroft at bay for over three years.

How fitting that this week our new organization, Compassion & Choices begins to take shape as well. A struggle waits on the horizon, and we are ready. Together Compassion in Dying and End-of-Life Choices are stronger, more prepared and purposeful than ever before. Our union is well suited for the hard times ahead.



CHALLENGING RELIGIOUS RESTRICTIONS

Compassion in Dying, the National Women's Law Center and forty-nine healthcare and consumer organizations have joined forces to protect patient rights. In a letter to the Joint Commission on Accreditation of Healthcare Organizations the groups asked JCAHO to adopt a policy that requires religiously sponsored hospitals to notify patients of restricted end-of-life care services.

Patients and their advocates need to ask if a faith-based hospital will honor: refusal of artificial nutrition and hydration, removal of life support, do-not-resuscitate order, and surrogate decision-makers for Alzheimer's patients. Often faith-based hospitals also require nonsectarian hospitals affiliated with them to abide by religious restrictions. Patients are

often unaware of these limitations and consent to admission or transfer before discovering disparities in end-of-life decision-making. Compassion supports the following changes in healthcare provider accountability:

- Hospitals must provide patients and prospective patients with written policies concerning religious or ethical restrictions prior to admission.
- Policies and patient notices must include a statement of the medical condition and the treatment affected by religious restriction.
- These policies must be prominently posted in patient, family and staff education, and marketing materials.

As of this writing, a JCAHO advisory committee is considering this proposal. Compassion In Dying, National Women's Law Center, American Civil Liberties Union, Catholics for Free Choice, NAACP, NARAL and other prominent organizations support this significant development.

Gratitude for 10 years of...

Loyal members and generous supporters who entrusted us with their vision for the future, their good wishes, and the resources to make our success possible;

Volunteers and advocates at Compassion In Dying of Oregon, Washington, Alaska, Northern California, Southern California, Hawaii, New York, Connecticut and Montana who have worked tirelessly to serve patients and families;

Patients who became plaintiffs and stood courageously to protect the rights of the dying. Your devotion and grace strengthened our resolve;

Family members who sacrificed anonymity and bravely faced public criticism to tell the story of the choice their loved ones made;

Thinkers and writers, the journalists, editorial boards and television and radio producers who brought Compassion's message of care and choice to the nation;

Medical experts who taught, inspired and guided us as we serve others;

Board members and advisors who shared their wisdom and then opened doors we could not have reached on our own.

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Photo by Graham Machdoe, courtesy of AmFAR

**Irene Diamond
1911 – 2003**

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IN LIEU OF FLOWERS

Our members have found many thoughtful ways to send their support to Compassion. Some methods we have anticipated and some have taken us nicely by surprise.

Andrew Turner was Pat Kistler Turner's beloved husband for fifty-two years. They met as children and fell in love forever. Andrew was also father to Andy, Lise, Amelia, and grandfather to five. He spent a career in the door and hardware business, and was a leader in professional associations. He loved to play music, and acted in community theatre. He played tennis and was a founding member of his local racquet club.

He taught adult Sunday school.

When Pat wrote Andrew's obituary for the Charlotte Observer, she remembered Compassion In Dying as the organization which gave them information and support about aid-in-dying.

Pat wrote at the bottom of Andrew's obituary, "In lieu of flowers, the Turner family suggests a donation to the charity of one's choice or a donation to Compassion In Dying. We urge you to write your state legislators to pass an assisted dying bill in North Carolina and ultimately the nation."

Over the next two weeks, Compassion received forty-one donations from the friends and

family of Pat and Andrew.

Thank you, Pat and Andrew, for thinking of Compassion in the midst of your grief and loss.

Thank you, to all our members and supporters, for innumerable gifts, prayers and kind words.

The **Reverend Shakti Kali Myokan Khan** is a Buddhist monk and a steadfast volunteer for Compassion In Dying of Oregon. Her peaceful presence and beneficence has helped many people.



Rev. Shakti Kali Myokan Khan

As a Buddhist monk, Shakti took a vow of poverty to live simply and humbly. When her mother passed away earlier

in the year, she was left a sizable inheritance.

Buddhist teachings tell that the greatest achievement is selflessness. Shakti made a decision to give her inheritance to causes which are important to her.

Shakti made two important gifts to Compassion. First, she insured the future of Compassion In Dying of Oregon with a large charitable gift annuity. With the second gift, she made a significant personal contribution to the national work of Compassion In Dying Federation.

Thank you, Shakti, for your foresight and generosity.

And now, let's move on together into the future.



COMPASSION IN DYING®
Federation of America

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ON THE ROAD



9/8 *Oregon's Model Implementation*

Ann Jackson, Barbara Coombs Lee & Alan Meisel, *Ten Years of Dignity Conference*, Washington, DC

9/12 *Safe Passage Into Dying*

Barbara Coombs Lee, *Dumbarton United Methodist Church*, Washington, DC

9/19 *Life, Death and All That Jazz*

Barbara Coombs Lee, *First Presbyterian Church*, Brooklyn Heights, NY

9/26 *Our Relationship with Death and Grief*

Gov. Barbara Roberts & Barbara Coombs Lee, *Writers on the Edge*, Newport, OR

9/30 *Health Law & Medical Ethics*

Kathryn Tucker, *Sarah Lawrence College*, Yonkers, NY

10/1 *The Wisdom of Wit*

Megan Cole, *Georgetown University*, Washington, D.C.

10/1 *Management of Pain: Licensure Issues*

Kathryn Tucker, *American College of Legal Medicine*, New Orleans, LA

10/10 *The Strength of Compassion and Choices*

Judith Fleming, *First Unitarian Society*, Minneapolis, MN

10/22 *End-of-Life Perspectives*

Helen Beum and Megan Cole, *Understanding the Diversity of Human Experience at Life's End*, Seattle, WA

12/9 *Policy Measures to Promote End-of-Life Care*

Kathryn Tucker, *National Conference of State Legislators*, Savannah, GA

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