

# connections

## aid-in-dying suit filed in Montana

**O**n Oct. 18, Compassion & Choices joined two terminally ill Montanans and four Montana physicians in a lawsuit against the state of Montana. The patients are suing for the right to die on their own terms.

The suit contends that mentally competent, terminally ill Montanans have privacy and dignity rights protected by their state constitution. These rights would allow them to obtain lethal medication from their physicians to self-administer for a peaceful death, if they choose.

Robert Baxter, 75, a retired truck driver from Billings, and Steven Stoelb, 53, a former logger and forest technician from Livingston, are represented by Mark S. Connell, a Missoula attorney, and Kathryn Tucker, Compassion & Choices Legal Director. Baxter suffers from lymphocytic leukemia, and Stoelb has Ehlers-Danlos Syndrome, a connective tissue disorder.

The suit challenges Montana's homicide statutes on several grounds under the Montana Constitution.

## New York Times Magazine article inaccurate

**O**n December 3, *The New York Times Magazine* published a lengthy article about Former Governor Booth Gardner and his support for an Oregon-style aid-in-dying law in Washington State.

By ignoring data from the Oregon experience, the article failed to accurately portray what legalized aid in dying might look like in Washington. This is a great disservice to Washington readers and voters, who can gain comfort from Oregon's ten years of experience with the *Death with Dignity Act*. Three troubling points, of many are:

- Bioethicist Susan Wolf speaks at length about her opposition to aid in dying on feminist grounds. Readers are told that women could be influenced by doctors into thinking their lives are not worthwhile, ascribing their "long-scripted cultural roles of sacrifice and suicide." Yet the Oregon experience has reflected no such trend. People who have used the 10-year-old law are nearly evenly split between men and women. Even Wolf admits that "Oregon's experience may mute her worries about the vulnerability of women."
- The author interviews Patricia King, an African-American bioethicist, who fears minorities would be hurt by an Oregon-style law. He vaguely cites King's references to studies about disparity in health care among different ethnicities. The Oregon data shows us that 10 years of the *Death with Dignity Act* does not disproportionately affect women, racial and ethnic minorities or other vulnerable populations. This information appeared in a widespread study published recently in the *Journal of Medical Ethics*.
- The author focuses on former Washington Governor Booth Gardner's deteriorating condition due to Parkinson's disease, painting him as a forgetful, feeble old man. Gardner is a fighter willing to stand strong in opposition to the status quo-even if that means opposing the wishes of his extremely religious family. He is valiantly fighting for a law which he knows he will not live long enough to see enacted.



Booth Gardner

## end of year contributions

*As you know, we have not sent year end mail solicitations in recent years. We hope that this newsletter gives you a sense of how diligently we are working to improve care and expand choice at the end of life. Please send a contribution so that we can continue our important work and our free counseling and advocacy services.*



## message

from the Executive Director  
CACNY moves mainstream

From the perspective of 5 years as Executive Director of Compassion & Choices of New York, I believe we have evolved from a small "outsider" group to become a mainstream, well-respected organization. We are now able to work successfully on a variety of critical end-of-life issues and activities with support from the public, from the health care community and from other relevant organizations and institutions.



David Leven, Executive Director, Compassion & Choices of New York.

Establishing our credibility as an important end-of-life organization with a broad and reasonable agenda has been a priority and our efforts have paid off. We have built effective relationships with leaders in palliative care and pain management, with geriatric physicians and with others working on end-of-life care. Our initiatives in developing palliative care legislation and our leadership role in introducing and securing passage of a bill requiring the NYS Department of Health to conduct education and outreach on health care proxies have been very important in developing our relationships and strengthening our credibility in end-of-life issues.

We have worked well with key NY State Legislators (such as the chairs of the Health Law Committees), the New York State Department of Health, various hospices, the Hospice and Palliative Care Association of New York State, the Medical Society of the State of New York, The New York City Academy of Medicine, and the Association of NYS Medical Schools,

Judith Schwarz, RN, PhD, our Patient Support Coordinator and I have both spoken at major and large palliative care, nursing, hospice, legal and pain conferences

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## AMWA steps forward as aid-in-dying leader

The **American Medical Women's Association** has stepped forward as a leader in the arena of end-of-life choice, adopting the nation's most progressive policy on aid in dying.

The professional group joined many outside observers in concluding that the availability of aid in dying has posed no harm to patients, vulnerable populations or physicians.

"We did so with the intention of continuing our advocacy for patient autonomy and dignity," said Susan Ivey, M.D., immediate past president of AMWA. "Our policy expressly refers to the practice of a physician prescribing medication to a mentally competent, terminally ill patient. The patient administers the drug himself or herself to bring about a peaceful death. We reject inaccurate, value laden terms such as 'assisted suicide' and 'physician assisted suicide.'"

The association determined that terminally ill, mentally competent patients have the right to hasten what could otherwise be an undignified, prolonged or extremely painful death. Doctors who agree with the practice should have the right to provide such a patient with the means and/or knowledge to use medication to hasten death. It also strongly supports the use of palliative and hospice care for patients who are terminally ill.

"The new policy adopted by the American Medical Women's Association on Aid in Dying is the most progressive in the nation," said Kathryn Tucker, director of legal affairs for Compassion & Choices. "It is the first time a mainstream national medical organization has openly endorsed passage of Oregon-style aid in dying laws."

**"The new policy adopted by the AMWA on Aid in Dying is the most progressive in the nation."**

— Kathryn Tucker, director of legal affairs for Compassion & Choices

## NYU Law School event promotes cause

In November, three of the leading proponents of aid in dying spoke on this important and timely topic.

**Sylvia Law**, Professor of Law, NYU Law School; **Barbara Coombs Lee**, President, Compassion & Choices; and

**Kathryn Tucker**, Director of Legal Affairs, Compassion & Choices presented a review of aid in dying over the past 10 years. Despite the fact that laws like the *Oregon Death with Dignity Act* have not yet been enacted elsewhere, the monumental success of the Oregon law gives hope that other states will replicate it. The presentations included:

- A brief review of *Washington v. Glucksberg* 521 U.S. 702 (1997), (argued by Ms. Tucker).



Sylvia Law, Barbara Coombs Lee and Kathryn Tucker (from left to right)

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# nursing home complaint to the NY state department of health sustained

Following a stroke, an elderly man with other serious health conditions was admitted to a nursing home in New York State. He was on life support at the time and was DNR (Do Not Resuscitate), but the nursing home did not inform the family about its policy not to remove life support until several days after admission.

The patient was conscious at the time of admission although unable to speak. He was able to make his wishes known, howev-

er, by squeezing his daughter's hand. He clearly expressed his wish, in the presence of his attorney, to be taken off life support.

After the family learned of the nursing home's policy not to remove life support, it took two weeks, with the assistance of our Patient Support Coordinator, Judith Schwarz, for the family to get the patient transferred to a hospice. There the request to remove him from life support was honored.

A complaint was filed at the request of the patient's daughter with the NYS Department of Health requesting that an investigation be conducted regarding the failure of the nursing home to comply with its obligation to inform patients of their rights regarding life support. The health department found that "the case allegations have been substantiated" and "the facility had incorporated a plan to prevent recurrence."

Before you or a loved one is admitted to a nursing home, you should inquire about the institution's policy on life support so that you can make an informed decision about admission.

## letters to the editor

Below is a letter from David Leven on pain management (one of four letters from David published this year in The New York Times).

September 17, 2007

### To the Editor:

*It is a tragic and terrible injustice that millions of people in poor countries die in pain because of inadequate treatment despite the availability of low-cost, effective treatments.*

*Yet the public health crisis of the undertreatment of pain inexcusably continues, even if not to the same extent, in wealthier nations, too.*

*A recent survey of 4,000 cancer patients in Europe revealed that two of three are in pain and that one-third of these patients sometimes had so much pain that they wanted to die.*

*Studies in the United States found that up to 41 percent of all cancer patients are in pain and that some 50 percent of seriously ill and dying patients did not have their pain managed.*

*A survey of New York State doctors reported in 2005 that occasionally or frequently one-third of them prescribed lower doses of an opioid drug for outpatients with chronic pain because of concern about investigation by a regulatory agency. Astonishingly, three-fourths of the doctors occasionally or frequently prescribed a non-opioid drug even when an opioid drug, such as morphine, may be indicated.*

*The severe undertreatment of pain is an urgent worldwide crisis. Corrective action can wait no longer.*

**David C. Leven**

*Pelham, N.Y., Sept. 10, 2007*

The writer is executive director of Compassion & Choices of New York, a nonprofit organization working to improve care and expand choice at the end of life.

## new legislation—old legislation

We have crafted bills that would increase the number of people who have health care proxies and are working hard to enact these bills.

One bill would require the New York State Department of Motor Vehicles to distribute, along with license and vehicle registration mailings, a health care proxy form and instructions as prepared by the Department of Health in collaboration with the Commissioner of Motor Vehicles. The Department of Motor Vehicles would conduct such mailings for the entire calendar year once every four years. We have not yet produced an effective financing mechanism, but our work on it continues.

A second bill provides that only one person need witness a health care proxy in most circumstances. Two witnesses are now required, unnecessarily in our view.

We are continuing to lobby for the *Family Health Decision Act* which would allow loved ones to make health care decisions for a person who loses decision-making capacity.

New York needs a safe harbor bill that would protect physicians who provide effective pain management to their patients and would punish those who do not. We have initiated a bill which we hope will be enacted next spring.

We are also working to ensure meaningful implementation of the *Palliative Care Education and Training Act*, to improve pain and palliative care, a bill that was enacted earlier this year as described in our last newsletter.

## message...Continued from page 1

and meetings. We have had over 50 speaking engagements in the past 2 years alone, well received by health care professionals, seniors, students, church congregants and others.

A number of organizations have been helpful to us in our outreach efforts to inform their communities or constituents about our services. These include the New York City Metropolitan Area Geriatrics Society, Council on Senior Centers and Services in NYC, AARP, NY Chapter, the Jewish

Association for Services for the Aged (JASA), and the New York State Association of Oncologists and Hematologists.

Although we are still relatively small and are not well known to some segments of the public and health care community, we have established Compassion & Choices of New York as a mainstream, innovative, credible and sometimes influential player. Through our many activities we are helping to improve end-of-life care and expand choice at the end of life.

## senior talks

During the past several months talks were given at a number of Senior Centers and Retirement Communities including, Van Cortlandt Village Senior Center, Roy Reuther Senior Center, Far Rockaway Village Senior Center, Sterling Glen of Glen Cove, The Woodlands, and Sterling Glen of Rye Brook.

## debunking the “slippery slope”

For years, our opponents have argued that legalized aid-in-dying will lead to a so-called ‘slippery slope,’ where vulnerable populations – such as the poor, people with disabilities, or racial minorities – will be coerced or manipulated into hastening their deaths. A new study published in the October issue of the *Journal of Medical Ethics* finally puts this unsubstantiated claim to rest. The study looked at Oregon and the Netherlands – where physician-assisted dying is legal – and found that vulnerable populations were not choosing aid in dying at disproportionately higher rates. The findings are quite conclusive and very encouraging. They are further evidence of the success of the *Oregon Death with Dignity Act*.



Margaret P. Battin, co-author of the study on legal physician-assisted dying

## Schwartz educating health care professionals

C&C of New York Patient Support Coordinator Judith Schwarz, RN, PhD continues to educate health care professionals on our work. She recently conducted an in-service training at Hospice of New York, gave a workshop at the International Palliative Care Conference in New York, met with leaders of the Visiting Doctors program at Mt. Sinai Medical Center, led a workshop at the New Jersey Hospice Palliative Care Organization and spoke to 125 nurses at a Nursing Research conference at the NYU Medical Center in Queens

## Leven was plenary speaker at major conference on pain

David Leven spoke to a plenary session of some 80 health care workers at a conference in New Haven “Helping Clinicians Manage Pain Safely...” sponsored by the Connecticut State Medical Society and the Connecticut Chapter American Society of Pain Management Nursing, among others. He discussed the under-treatment of pain as a public health crisis and what steps, particularly legislative, Connecticut could take, as has New York, to begin to address this problem.

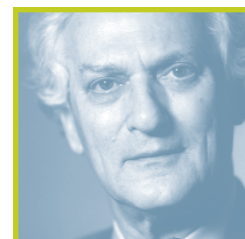
## talking to high school students in Schenectady and law students and others in Albany

Engaging in a debate on aid in dying with two hospice workers at a Schenectady high school, David and an Albany Law School student clearly prevailed, based on the response of the 120 students in attendance. Almost all of the questions were directed to the hospice physician and chaplain.

On the same day, at Albany Law School, David spoke to some 60 law students, health care workers and citizens on why aid in dying should be supported, the remarkable success of the *Oregon Death with Dignity Act* and why aid in dying will eventually be the law across the nation.

## Dr. Cassell gives talk on suffering & death

In June, to a group of some 125 people at The New School, Dr. Eric Cassell, an expert on end-of-life care, gave an inspiring, very well received talk on “When Suffering Patients Seek Death.” Dr. Cassell made it very clear that people who are suffering at the end of life do not really want to die; they just do not want to live under their existing circumstances which, for them, have become intolerable. He also pointed out that people who are suffering at the end of life are not usually depressed although their symptoms are similar. These are people who decide to die with dignity, Dr. Cassell asserted and if they hasten their deaths, even with lethal medicines, they are not committing what



Dr. Eric Cassell

has been wrongly termed suicide. For those terminally ill patients in Oregon who take lethal medicines prescribed by their doctors, the correct terminology is “aid in dying,” Dr. Cassell said.

## Law School...Continued from page 1

- An overview of terminology/importance of language, evolution of terminology re aid in dying and the importance of using correct terminology.
- Passage of the *Oregon Death with Dignity Act* (ODWDA).
- Legal challenges to ODWDA.
- Experience in Oregon with implementation and how successful the law has been
- Data indicating that none of the concerns or objections raised by opponents or skeptics have materialized.
- The state’s principal argument against ODWDA was risk of abuse, but there has been no evidence of such abuse.
- The value of the data to those seeking to pass similar laws in other states.