



compassion & choices
of new york

Fall 2005 Issue

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help our movement grow

If we are going to continue to make progress in all of our many activities to improve end-of-life care and expand options for all of us at life's end, we need to engage in many more efforts. We need your help. Please use the enclosed questionnaire to send us information that will be helpful.

1. We need more members and supporters. Two thousand members in a state with 18 million people, only one of every 90,000, is not enough. If you are not a member, join C & C. Please list the names of up to 10 friends or relatives, potential members, on the form enclosed and return it within the next week with your permission to use your name if we contact them. As important, we need major donors, people who might give \$1,000 or \$10,000 or \$100,000 or more. Do you know people who you think might be interested? Let us know. Is C & C in your will?

2. We need to be out there making more presentations. Twenty speaking engagements a year are not enough in NYC and the area. We should have hundreds. Please consider connections you have to religious, community, civic groups, professional organizations, businesses, colleges, and senior groups. All kinds of groups are interested in learning about our issues.

3. What connections do you have to anyone in the media? Tell us who they are. If you see a story or column on end-of-life issues, write a letter to the editor, or let us know of your interest and we can help prepare a letter for you or for us to send.

4. What connections do you have to sympathetic health care and other relevant professionals including, doctors, nurses, social workers, psychologists and lawyers. We would like to know who they are so we can inform them about C & C and hopefully get to speak to the organizations they belong to.

5. Are there meetings or conferences that you attend where we might be able to speak or provide

information about C & C? Who are the contact people we might reach out to with your help?

6. Be a good will ambassador with your friends, neighbors, relatives and colleagues. When you are with family and friends, talk about this movement and about C & C specifically. Tell them how important it is to have a health care proxy and that we can supply them with the necessary forms and provide guidance in completing them. Tell your loved ones we can help with pain management issues. Fifty to seventy million people have chronic pain and many of them are getting inadequate pain care. We can help get them better pain care. We can give advice on filing complaints and even lawsuits, if people have suffered unnecessarily because of serious undertreatment. We will discuss any end-of-life issues that are of concern.

Gonzales case presents media opportunities

Compassion & Choices was prominent in the national and local media on the *Gonzales v. Oregon* case. In New York, Executive Director David Leven was on a number of radio and television programs and also had a letter and an op-ed in the print media, as listed below:

Fox Cable Radio, Alan Colmes Show, (1 hour with senior attorney from Family Research Council), RNN TV (with Legislative Counsel for National Right to Life Committee), Op-ed in *The Journal News* (Westchester Rockland), Dallas-Ft. Worth Radio, KLIF, Coast to Coast Talk Show Interview, WVOX radio, Westchester (with Chair of Iona College Political Science Dept.), Letter to the Editor of *The New York Times*.

Judith Schwarz, RN, PhD, C & C of NY patient support coordinator, and David Leven were on the WBAI radio show Health Styles, for a one half hour program on physician assisted dying. Compassion and Choices of New York Board President, Florent Morellet was interviewed on the WBAI Cat Radio Café program.

message from the executive director

On October 5, the U.S. Supreme Court heard arguments in *Gonzales v. Oregon*, a challenge to Oregon's physician aid in dying law. The issue before the court is whether the U.S. Justice Department can use the federal Controlled Substances Act to block the state-regulated medical practices in Oregon, which permit physicians to prescribe lethal drugs to people who are terminally ill so they can hasten their own deaths.

The issue is critically important to all of us who want control as we die. A ruling for the federal government would abrogate the will of the people in Oregon, where 60% of the voters rejected a 1997 attempt to overturn the law approved by the voters 3 years earlier. It would also be contrary to the wishes of our nation's citizens, as polls consistently show that two-thirds of the public support the right of the terminally ill to end their lives peacefully. If Oregon wins, other states, including New York, could follow its lead.

The Oregon law has been an extraordinarily successful experiment, by any measure. None of the anticipated problems raised by opponents have materialized. There have been no abuses. Contrary to what was predicted by opponents, the law has been used sparingly. Only 1 out of 1000 deaths occurring in Oregon (just 208 people in 7 years) result from lethal medication prescribed under the Oregon law. Yet thousands more are comforted, knowing that they have an escape from terminal misery. All but 6 people who have used the law have had health insurance, most were college educated and a majority had strong family support systems. Some 90% were enrolled in hospice and received the best possible end-of-life care. Aid in dying is increasingly recognized as belonging on the continuum of good end-of-life care, a last resort in the face of unrelieved suffering. Thanks to its aid-in-dying law, Oregon now has better end-of-life care than a large majority of states.

In Oregon excellence in care at the end of life is a priority. Aid in dying is legal, above ground and stringently regulated, not the underground, illegal and unregulated practice that is common elsewhere. A recent study of 6 other states revealed that



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

"We hope that the Supreme Court will affirm the lower court decision and allow Oregon residents to continue to die on their own terms."

1 in 250 people die by physician assistance, a rate 4 times higher than Oregon's. Under the Oregon law, 94 people who were prepared to kill themselves with guns were able to obtain lethal medicines and were spared this awful and undignified way of dying with its tragic consequences for loved ones. If the federal government wins in the Supreme Court, it is likely that some in Oregon will once again turn to the underground practice of assisted dying. As in the past, others will see violent suicide as their only recourse as in the face of unbearable suffering.

The federal government should not interfere with the liberty of its citizens to make hard choices about life and death. For the government to do so is both coercive and paternalistic. The federal government has no business telling physicians that they cannot prescribe lawful medicines for their patients. This is an area that has been traditionally state-regulated and nothing in the language of the Controlled Substances Act or the intent of Congress appears to give the Attorney General, untrained in the field of medicine, the right to control medical practice within the states.

We hope that the Supreme Court will affirm the lower court decision and allow Oregon residents to continue to die on their own terms.



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connections



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educating professionals

We are increasingly making efforts to inform and educate professional in health and other related fields about our work.

At **Yale Law School**, David Leven debated Andy Imparato, President of American Association of People with Disabilities on physician aid in dying in connection with *Gonzales v. Oregon*.

Judith Schwarz, RN, PhD, C & C of NY patient support coordinator, participated in a 2-day conference entitled, "Controversies in End of Life Care: Terri Schiavo's Lessons" at **Smith College** over the Columbus Day weekend. She presented a paper on nurse-assisted dying, and co-facilitated 2 workshops on issues re assisted dying - one of which involved a NY Compassion case that was co-presented with Dr. Linda Ganzini of the Oregon Health Sciences University.

David taught several classes on end-of-life issues to nursing graduate students and nursing students at **College of New Rochelle School of Nursing**. He emphasized the need for nurses to be advocates for their patients on a wide range of issues including: obtaining effective pain management, honoring health care proxies and hastening death by stopping eating and drinking.

Judy and David spoke to about 30 social workers at a meeting of the **Westchester Chapter of the New York State Society for Clinical Social Work** on physician aid in dying.

Judy spoke to nurses in a master's degree class on palliative care at NYU.

Compassion & Choices of New York Board President Florent Morellet was on a panel at **The New School** sponsored by the Gay and Lesbian Medical Association on the topic: "What if Terri Schiavo Were Gay? Planning For the End of Life in the LGBT Community."

Florent was honored at **The Lesbian, Gay, Bisexual & Transgender Community Center** and spoke to over 200 people about his experiences with death and dying and the importance of choice at the end of life.

David spoke to about 175 lawyers and their clients of the **Cummings & Lockwood** law firm on health care proxies and end of life communications between patients, their family members and physicians.



Professor Connie Vance, College of New Rochelle Nursing School and David Leven.



Florent Morellet, President of Compassion & Choices of New York.

counseling patients

Many of the calls we receive are from socially isolated elderly patients who have outlived or are estranged from family and friends, and suffer from multiple chronic ailments that are not clinically well managed. These calls require a great deal of time and tact - we try to refer these patients to competent health care professionals for care.

However, recently a call was received from the supportive daughter of a 97 year old woman who was a resident of a local nursing home. This elderly woman was both decisionally capable and determined to control the circumstances of her dying. She informed the medical staff of her nursing home that she had decided to hasten her death by refusing food and fluids. Her physician responded by putting her on a suicide watch and threatening to have her transferred to a hospital if she persisted in refusing food and fluid. Judy has begun to counsel this family about how to successfully navigate through this difficult terrain - a process that needs careful planning, assistance by hospice clinicians along with appropriate analgesia, and successful collaboration with the nursing home staff.

meeting with seniors

Our Senior Citizen initiative continued as we met with seniors at a variety of locations.

David Leven spoke to seniors at the **Irvington Senior Center** and to **Scarsdale** seniors about health care proxies, pain management and hastening death and distributed proxies to those present.

The Older Women's League, Hudson Valley Chapter, hosted a talk by David about end-of-life health and relevant other health legislation pending in the NYS Legislature at their summer meeting. These included the pain legislation, Family Health Care Decisions Act and medical marijuana bill, all of which they agreed to support and to communicate their support to key and their own legislators.

At a **Lincoln Park Seniors** meeting in Yonkers, David spoke about the *Gonzales v. Oregon* case and its importance to those of us who support choice at life's end as well as about health care proxies and pain management.

David also met with the **AARP Gun Hill Chapter in the Bronx** to discuss health and end-of-life issues. He handed out health care proxies to the audience, a majority of whom had not completed one. David urged that they complete one and that others make copies of the proxies and distribute them to their adult children.

aid in dying facts from Oregon

Compassion & Choices of Oregon, our sister organization, has gathered useful and interesting information on those who seek to use Oregon's law that is not included in the Oregon Department of Human Services' annual report. Such facts as:

Political identification: 43% self identify as Republican, 41% as Democrat and the remainder having no preference or being Independent.

Religious affiliation: 91% believe in a higher being. Of the total who gave a religious preference, 16% identified with a Protestant Church, 7% with the Catholic Church, 2.5% with a Jewish Synagogue, 2% with a Unitarian Church and 1% with a Buddhist Temple.

Age range: The ages ranged from 20 to 103. The average was 69.

Duration: The average length of time from first request for assistance to death is 133 days.

We believe the most significant statistic - one that reflects how well our law works - is the prevention of violent suicides. Our law has provided comfort and relief to thousands and has prevented at least **94 terminal-ill Oregonians from committing violent suicide.**

pain bills: two bills pass assembly; meets Sen. Hannon

The leadership efforts of Compassion & Choices of New York to improve pain treatment and palliative care continued this year and some progress has been made. A summary of the bills and actions taken on them by the NYS Legislature is below:

A.7640 (GOTTFRIED), CLINICAL EDUCATION

Purpose: Requires medical school education to include education and training in pain management; end-of-life care.

Final 2005 Action: Referred to Assembly Higher Education Committee

A.7642(GOTTFRIED)/S.5017(HANNON), CME

Purpose: Requires that all health care practitioners complete course work or training regarding pain management; creates an advisory committee comprised of 12 members appointed by the Commissioner of Health and the Commissioner of Education to help the Department of Health develop, review and implement the appropriate educational standards.

Final 2005 Action: Passed Assembly 129-1

A.7643(GOTTFRIED)/S.5016(HANNON), SAFE HARBOR

Purpose: This bill protects health care professionals from criminal liability and professional discipline for prescribing and administering pain medication, when they act within accepted professional standards.

Final 2005 Action: Passed Assembly 134-1

Over the summer the proposed Palliative Care Education and Training Act was improved. It would provide almost five million dollars to enhance medical school education and residency training in the areas of pain treatment and palliative care and establish Centers for Pain Management Excellence. It would also create an advisory board of experts in the field to work with the NYS Department of Health.

A meeting with Senator Kemp Hannon, Chair of the Senate Health Committee on October 5 went very well. Compassion board member Peter Rogatz, David Leven and Vince Marrone, our lobbyist, attended along with a pain patient and 5 physicians, in addition to Peter, who are experts in pain management and palliative care. They

included Dr. Diane Meier, Director of Center to Advance Palliative Care of the Hertzberg Palliative Care Institute at Mount Sinai School of Medicine; Dr. James D'Olimpio, Director of Palliative Medicine Service North Shore University Hospital; Dr. Hannah Lipman, Fellow, Brookdale Department of Geriatrics and Adult Development, Mount Sinai Medical Center; Dr. Joseph Weiner, Director, Palliative Care Service, Long Island Jewish Medical Center; Dr. Carole Agin, Director of Pain Management, Stony Brook University Hospital. A pain patient of Dr. Meier's also attended. Sen. Hannon was very receptive and supportive of the concepts outlined in the draft Palliative Care Act; he didn't sign off on every detail and provision, but agreed that it was something that has the potential to move forward in the Senate and said he would like to work with Assemblyman Richard Gottfried, Chair of the Assembly Health Committee, on the bill.

We agreed to try to keep this group together, along with the very articulate and compelling patient who attended the meeting (and did a terrific job of personalizing the issue), for advocacy in Albany in 2006.

more doctors support physician aid in dying

According to American Medical News, nearly 6 in 10 physicians now support physician aid in dying. The independent market-research firm HCD Research randomly surveyed 677 doctors of whom 59% expressed the view that doctors should be legally permitted to dispense prescriptions for life-ending medication to terminally ill patients who request it.

world right to die conference in Toronto

The 2006 World Conference will take place from September 7-10, 2006 at the Sheraton Centre in downtown Toronto. Mark your calendars. The host organization, Death with Dignity, is seeking ideas and suggestions on the program, topics to be addressed, workshops or breakout sessions, and speakers. Contact Kathy St. John, Executive Director, Dying With Dignity, Tel: 416-486-3998, ext. 22, E-mail: kstjohn@dyingwithdignity.ca.