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Washington voters approve Death With Dignity Act

The passage of Washington's I-100 is a "turning point on the path to human liberty. No terminal Washingtonian will ever have to shoot themselves or use other violent means again. We hope someday to be able to say the same for patients in the other 48 states," said Compassion & Choices President Barbara Lee.

"Dignity has prevailed over dogma," Lee said, "Opponents peddled lies and half-truths about Oregon's Death with Dignity experience, but voters weren't buying it. They decided end-of-life decisions are too personal, too precious and too sacred, to trust in the hands of government, politicians and a few religious leaders. Now, dying Washington residents can turn to legal aid in dying instead of feeling forced into violent, crude methods to end their suffering. We know when aid in dying is legal, end-of-life care improves for everyone. This happened in Oregon, and it will happen in Washington as well."

Lee pledged to continue working to bring choice to terminal patients in the 48 states where aid in dying remains illegal, "The people of Washington opted for individual liberty, personal autonomy and freedom of conscience. We will continue to fight for these values on behalf of terminal patients and their families in the remaining states. These battles champion truth over lies, dignity over dogma and free will over blind obedience."

Lee praised "thousands of volunteers who gave of their time, energy and money to support patient choice. Their dedication and labor was nothing short of heroic. All those who will die from this day forward, free and empowered with choices whether they exercise their right to death with dignity or not, owe them a debt of gratitude."

Yes - Votes: 59%
No - Votes: 41%

Washington becomes second state to legalize aid in dying, campaign has moved patients' rights forward: Oregon experience shows aid-in-dying law benefits all at end of life, provides comfort and control to terminally ill, ends violent deaths.

American College of Legal Medicine adopts policy supporting aid in dying

The American College of Legal Medicine has adopted a policy supporting aid in dying, joining two other major medical organizations. The ACLM, along with the American Medical Women's Association and the American Medical Student Association, all recognize that Oregon-style Death with Dignity laws demonstrate no harm to patients. On the contrary, they have proven to reduce harm by eliminating underground, "back alley" aid in dying and have galvanized improved end-of-life care in that state.

Their support reflects a clear trend among medical experts to examine the Oregon experience and adopt policy supporting legalization of this end-of-life option. The ACLM policy recognizes patient autonomy and reinforces the right of a mentally competent, terminally ill person to achieve a peaceful death under proper safeguards.

The ACLM was the first professional organization to publicly reject use of the term "suicide" when referring to the choice of a mentally competent, terminally ill person to seek a peaceful death.

In the mid-1990s, the college submitted an amicus brief to the United States Supreme Court in support of patients and physicians seeking a constitutional right to aid in dying. In this brief the ACLM stated, "The term 'physician-assisted suicide' is arguably a misnomer that unfairly colors the issue, and for some, evokes feelings of repugnance and immorality... It seems inappropriate to characterize requests for treatment that end life, made by suffering, terminally-ill patients, as any form of destruction or ruination of their interests."



message

from the Executive Director

hospice – wonderful but underutilized in New York

We all want to die well. Too many of us are unable to, but more of us would if we were in hospice near the end of our lives. Unfortunately, across New York State people are not taking advantage of hospice.



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

I admit that 11 years ago when my mother was dying I did not know what hospice was and the many significant benefits it provides the terminally ill and their family members. Having worked for Compassion & Choices of New York the past six years, I now know from the experience of numerous patients whom we serve nationally and in New York, from studies and from anecdotal evidence, that hospice is an excellent but incredibly underutilized program. Rates of satisfaction of family members who would recommend hospice to others exceed 90%.

Eligible for enrollment when survival is unlikely beyond six months, patients benefit enormously but so also do their loved ones. With an interdisciplinary team providing holistic care to ensure the best quality of life for people in the final chapter of their lives, physicians, nurses, social workers, chaplains, therapists and others, all trained in end-of-life care, work together in the best interests of patients and their loved ones. After enrollment, a plan of care is developed to meet the needs and desires of the patient and family. Excellent pain and other symptom management are provided by compassionate, caring hospice staff. Medicare covers most costs for the elderly patient. A recent Duke University study found that hospice reduced Medicare costs by an average of \$2,309 per hospice patient.

Studies show that while some 80% of us want to spend our last days at home, not in an institution, only about 25% of us do. Nationally, only 36 % of us die in hospice,

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The Newsletter of Compassion & Choices of New York

Right to Know Act signed into law in California

Governor Schwarzenegger has signed the *Terminal Patients' Right to Know End-of-Life Options Act*. The act is the first in the nation to provide terminally ill patients with a full disclosure of, and counseling about, all available legal and ethical end-of-life care options. When requested, information about hospice care, refusal or withdrawing of life-prolonging treatments, voluntary stopping eating and drinking (VSED), palliative care and palliative sedation will be discussed with the patient. The act also requires that health care providers who do not wish to comply with a particular patient's choice must refer or transfer the patient to another provider.

"Dying patients needlessly suffer due to a lack of essential information. As a result, many spend their last days in agony. Too many patients make the most important decision of their lives – how they will live their final days – without being fully informed of their legal rights," said Barbara Coombs Lee, president of Compassion & Choices, sponsor of the measure. "The Right to Know End-of-Life Options Act would require physicians and health care providers to provide a full range of information about options when patients request it. The act puts the information and power to choose in patients' hands."

Thirty years ago, California led the nation by giving people the right to express their wishes for health care in advance. This next step will ensure that many terminally ill patients have all of the information that they need to make timely and informed decisions regarding their care. Information and counseling regarding end-of-life care options is essential for many terminally ill patients and their families. It can help patients weigh all of their options and make informed decisions that best meet their needs. It gives the physician an opportunity to discuss the benefits and disadvantages of all available treatments, and it can facilitate earlier access to hospice care.

Medical Orders for Life Sustaining Treatment (MOLST) now approved statewide for NY

Governor David A. Paterson has signed into law a bill that helps to ensure that a person's end-of-life wishes are followed whether the person is at home, in a nursing home or in any other non-hospital setting. The new law recognizes Medical Orders for Life Sustaining Treatment (MOLST). A seriously ill patient, after talking to her doctor, may ask to have the MOLST form completed, specifying the kind of care she wants at the end of life. The MOLST form is bright pink — so it can be easily identified by all health care personnel — and contains physician's medical orders that are to be honored at any site of care in the community.



NY Governor David A. Paterson

Gov. Paterson said, "People should be allowed as much say in their end-of-life care as they would have at any other time. This bill will allow many people who are critically ill to make enduring decisions on the care they will receive. These will be difficult decisions for every person to make, but they should have the freedom to make them."

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Dr. Muller gives talk at Mount Sinai Medical Center

In June, Dr. David Muller, Dean of Medical Education at Mount Sinai Medical Center, a founder of the Visiting Doctors Program and a national C&C board member, gave a talk at Mount Sinai Medical Center sponsored by Compassion & Choices of New York. His talk, entitled "When Dying Patients Seek Death: Evaluating Meaning and Responding Appropriately", before some 125 health care professionals and citizens, was extremely informative. Dr. Muller described the complexities of situations where dying or seriously ill people wish to hasten their deaths and the need for health care professionals to be trained to respond appropriately and supportively. In one situation which he encountered, a frail 87 year old woman with a number of chronic illnesses told Dr. Muller that she wanted to die. He described the case and his compassionate and supportive interactions with her.



Dr. David Muller, Dean of Medical Education at Mount Sinai Medical Center, a founder of the Visiting Doctors Program and a national C&C board member

Dr. Schwarz is published in the American Journal of Nursing

C&CNY Clinical Coordinator, Dr. Judith Schwarz, has an article in the August edition of the American Journal of Nursing, "I Can't Help You with That': *When terminally ill patients wish to hasten their dying, nurses can, and should, help.*" She concludes the article, stating: "Often, good palliative or hospice care alleviates the suffering of the dying. Nonetheless, a small but significant proportion of dying patients suffer intolerably. Although most don't seek a hastened death, some will ask about it. And when they do, nurses experience a great moral conflict: they want to help their patients die well, yet they don't want responsibility for helping them to die. Patients who are dying have no control over the inevitability of their death. When they suffer intractable symptoms, they should receive complete end-of-life support from nurses. It's the least we can provide."



Dr. Judith Schwarz, C&CNY Clinical Coordinator

Leven speaks at American Association of Justice conference

In July, C&CNY Executive Director David Leven spoke to 65 trial lawyers at the American Association for Justice Conference in Philadelphia on bringing cases for inadequate pain management and failure to respect end-of-life choices. He noted that the right to have effective pain management is increasingly being recognized and legal redress is sometimes appropriate when physicians fail in their obligation to provide effective pain care to their patients. Doctors should be held accountable when they fail to provide effective pain care and when they fail to respect and honor the end-of-life wishes of their patients. David described the California case where a jury awarded \$1.5 million to the survivor of a patient who did not have his pain treated effectively when hospitalized during the last week of his life (reduced to \$250,000 by statute) and which resulted in mandatory education for medical students and continuing education for physicians on pain management and palliative care. He also described the legislation in New York providing \$4.5 million for medical school and post medical school training to improve pain management, palliative and end-of-life care.

hospice...Continued from page 1

most in hospice programs at home, some in hospitals with hospice beds or in freestanding hospices and increasingly some in nursing homes with hospice beds. New York, with hospice enrollment below 30 percent, ranks 46th nationally in the use of hospice care. This must change.

Why is there such a disconnect between the positive benefits of hospice and its low utilization, to the detriment of those at the end of their lives, their families and the medical profession? There are a number of reasons. Too many people, including physicians, still have difficulty confronting death and dying. Doctors should talk with their patients about condition and prognosis, unless the patient makes clear that such information is not wanted. However, often physicians do not do so, instead recommending continued, costly, therapies that rarely prolong life or add to the patient's quality of life. Inexcusably, too many dying patients are never referred or given the option of being referred to a hospice. Some are referred only in the final days of their lives (about a one-third of patients die within seven days of admission to hospice). And cultural differences and barriers persist, based to some extent on an understandable mistrust of the health care system, resulting in even less use of hospice by people of color than by others.

Each of these issues needs to be addressed more aggressively.

Hospice offers compassionate and competent end-of-life care, preventing many bad deaths. It is time for the medical profession in particular and all of us with knowledge of the many positive benefits of hospice, to be ambassadors for hospice, and to take advantage of this wonderful but underutilized program.

MOLST...Continued from page 1

The MOLST form expands patients' instructions beyond a simple do-not-resuscitate order, to include questions of intubation and medication, which many end-stage patients would like to control for themselves as much as possible. The MOLST form will specify, among other wishes, whether or not the patient wants to be resuscitated or intubated, to be hospitalized or receive medication. MOLST is based on a national model that has been shown to improve the likelihood that a patient's wishes will be respected. New York is one of six states to adopt this kind of program.

Leven and Schwarz speaking out

In recent months Executive Director David Leven and Clinical Coordinator Judith Schwarz have been educating numerous health care professionals and seniors. With grants from different foundations for an educational campaign for seniors to learn their health care rights and how to communicate effectively with doctors, David has spoken at a number of senior centers. These include Parkside, (Bronx) Sleepy Hollow (Westchester) City Island (Bronx) Lenox Hill (Manhattan), Highbridge (Bronx), Harlem (Manhattan), Kew Gardens (Queens), and Davidson (Bronx). Please contact David if you would like to have him speak at a senior center, retirement community or other venue for seniors.

Judith Schwarz conducted a workshop for the Greater NY Chapter of the National Association of Professional Care Managers; "At the End of Life: Compassion & Choices," and provided an in-service program at the NYC Chapter of the National MS Society.

About a year ago Judith Schwarz had an idea for a panel discussion about the underground practice of aid in dying that exists across the country. Judith routinely attends the annual conference held by the American Society of Bioethics and the Humanities, and knows how infrequently the topic of aid in dying is included for discussion in workshops. At last year's conference, she began to reach out to like-minded scholars who have done seminal research in this area, several of whom agreed to participate. The panel presentation, entitled

"Dying Behind Closed Doors: Bringing Hidden Consequences of Illegal Aid in Dying to Light" was presented to a large audience of physicians, nurses, philosophers and others interested in palliative end of life care. The following objectives for this panel included: 1) to identify and discuss the personal and professional consequences of aid-in-dying from the perspectives of family members and clinicians who participate in a hastened death in an illegal environment; 2) to examine how slippery-slope pressures might apply in non-legal contexts, and 3) to discuss what clinicians should consider if asked to provide aid-in-dying.

Judy presented her doctoral research data regarding the consequences to nurses who choose to respond to patients' requests for assistance in dying. Those consequences include feelings of moral conflict, guilt, fears about crossing ethical/legal boundaries, which combine to cause moral distress that may lead some nurses to abandon the profession. Many nurses respond in secret to such requests; some hospice nurses leave it to family members to figure out for themselves how they might help their loved one to have a hastened death. Although stipulating that she was not assuming an advocacy role on the panel – and that her research findings were developed before her C&C association, Judy did include a slide that described the national work of C&C as a resource for decisionally capable, terminally ill patients who wish information about end-of-life options.

Montana court hears terminally ill patients' landmark lawsuit seeking right to death with dignity

Montana's First Judicial Court heard a landmark lawsuit in October by terminal Montana patients, asserting a right to a dignified death protected by the Montana Constitution's guarantees of privacy, dignity and equal protection. The patients' and physicians' attorneys argued before Judge Dorothy McCarter, asking for court approval for the patients to obtain medications they could self-administer to bring about a peaceful death, if suffering becomes intolerable. Bob Baxter of Billings and Steven Stoelb of Livingston, two Montana patients facing the end of life,

were joined in the lawsuit against the State of Montana by four distinguished Montana physicians and Compassion & Choices.

"I value my independence and dignity, as do all Montanans," said Baxter, a 75-year-old retired truck driver. "I have lived an independent life. Now, I am dying of lymphocytic leukemia. It's a horrible disease. It's painful, limiting, and I'm losing my ability to live life. I want the choice to die with dignity if my pain becomes intolerable. I want my doctor to be able to prescribe medication for a peaceful death. This is my personal choice, based on my personal values

MOLST, health care proxies & living wills

MOLST does not take the place of a living will or health care proxy. These are three different kinds of advance directives; here are the key differences among them:

MOLST is a medical order form, signed by a physician that tells others your wishes regarding life-sustaining treatment. MOLST is applicable to people with a serious health condition.

A **HealthCare Proxy** designates an "agent" to make health care decisions on your behalf only if you are unable to make decisions yourself.

A **Living Will** permits you to state in advance your wishes if you develop a condition that prevents you from communicating your wishes. It can be useful and may provide "clear and convincing evidence" of your wishes, the legal standard of proof which must be satisfied in order to be binding under New York State law.

and beliefs. I want to be able to gather my loved ones and die with dignity in my own home. I should be free to make my choice without the state making the decision for me."

Compassion & Choices Legal Director Kathryn Tucker, lead counsel in the two federal cases asserting a right of this nature under the U.S.



Kathryn Tucker, C&C
Director of Legal Affairs

Constitution, teamed with well-known Montana litigator, Mark Connell, in arguing for the patients and physicians. "Montana's Constitution protects the decision-making power of its citizens in the most intimate and fundamental areas of their lives, particularly where the overlapping rights of privacy, individual dignity, equal protection and due process are concerned," said Tucker. "Whether to endure further suffering or, instead, to cut such suffering short, is an intensely personal, private decision which an individual makes based upon his or her most deeply held values and beliefs. If Montana's right of privacy protects anything, surely it protects this decision."