

# connections

## o u t r e a c h

### Leven lecturing to professionals & students

David Leven has been lecturing to social work and nursing students, many of whom have an opportunity to work with and help dying people and those in pain. During the past several months, David lectured on end-of-life issues and choices to graduate social work students at Hunter College School of Social Work and Fordham University Graduate School of Social Service and both graduates and undergraduates at College of New Rochelle Nursing School.

### Schwarz speaks to health care professionals

During the past several months Judith Schwarz, RN, PhD, Clinical Coordinator, Compassion & Choices of New York:

- Conducted a nursing grand rounds on Ethical Issues in End of Life Nursing Practice at Bronx-Lebanon Hospital;
- Delivered a lecture for the David Rogers Health Policy Colloquium at NY Cornell-Weill Medical College. Her talk, entitled, "What's in a name? Assisted dying or assisted suicide? Reflections on the Oregon experience," was presented to some 50 medical students and faculty and generated a lot of discussion and questions.
- Spoke at an Ethics luncheon, to Mt. Sinai Medical Center physicians, medical students, nurses and social workers on "Dying in secret: the practice of aid in dying in legal and illegal environments and the role of Compassion & Choices";
- Conducted a workshop (standing room only) in Chicago for the annual conference of Professional Geriatric Care Managers on the topic, "At the end of life- Compassion & Choices: a guide for end-of-life decisions." There was a good deal of positive feedback and workshop members evidenced considerable interest in the concept of Voluntarily Stopping Eating and Drinking (VSED).

### in the media

In a *New York Times* supported blog, Jane Gross, a *Times* health columnist, quotes Judith Schwarz extensively, especially on stop eating and drinking, in "End-of-Life Choices: A View From the Front Lines" <http://newoldage.blogs.nytimes.com/2008/12/11/end-of-life-choices-a-view-from-the-front-lines/>

David Leven had a letter to the editor published in *The New York Times* on pain management and training for physicians.

## Leven playing leadership role on legislation

### Family Health Care Decisions Act: this could be the year!

David Leven was a team captain on a lobbying day in Albany on the *Family Health Care Decisions Act*, which would give surrogates the right to make health care decisions for their loved ones who lose the ability to make decisions for themselves where there is no health care agent. He drafted a position paper for the Westchester End-of-Life Coalition that was presented to key legislators and/or their staffs.

### other legislative initiatives of C&CNY

Several bills have been introduced, mostly by the chairs of the assembly and senate health committees, Richard Gottfried and Thomas Duane, at David's urging to improve care and expand choice at the end of life. These include bills that would require physicians to have discussions with their dying patients about palliative care and end-of-life options (see Message from Executive Director), protect physicians who prescribe opioid drugs for their patients who are in pain when doing so in accordance with the reasonable standard of care of the profession including an accepted guideline, and reducing the number of witnesses to the signing of a health care proxy from two to one.



Senator Thomas Duane



Assembly member  
Richard Gottfried

## message

from the Executive Director

### avoiding the inevitable: conversations about end of life

It has been suggested that Americans are the only people on earth who believe that death is negotiable. It is not. Yet, we deny and try to avoid death. Conversations about death are uncomfortable for those who are dying and sometimes as much or even more so for loved ones and health care professionals. And so end-of-life conversations do not take place often enough between health care professionals, particularly doctors, (see articles in newsletter on this topic) and their patients. This is to the detriment of patients, their loved ones and good medical practice.



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

This has to change. Why? Because the law requires it. Why? Because 2.5 million people die in this country each year including 155,000 in NY. Why? Because too many people are having bad deaths; too many patients are being treated to death; too many are being treated excessively, causing unnecessary suffering that could be avoided if end-of-life conversations took place and patients were able to make informed decisions. This must change. Why? Because all of us care about how we die and how our loved ones die. We all want good, peaceful deaths for ourselves and for those we love.

Patients should be empowered to decide what is the best course of action for them, as autonomous individuals. Adequate information must be provided to every patient about her disease, prognosis and the potential benefits, risks and burdens of the different treatments, care and end-of-life options available. This should be done in consultation with health care professionals and loved ones.

Remedial legislation is required to ensure that physicians have discussions with their dying patients which will empower their patients to make end-of-life care decisions that are right for them.

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## end-of-life discussions related to less aggressive care, earlier hospice referral

Associations Between End-of-Life [EOL] Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment," is an excellent article on a study reported in the Journal of the American Medical Association (JAMA). According to the article, "End-of-life discussions are associated with less aggressive medical care near death and earlier hospice referrals. Aggressive care is associated with worse patient quality of life and worse bereavement adjustment."

The study, by a group of Boston researchers, set out to "determine whether end-of-life discussions with physicians are associated with fewer aggressive interventions." Three hundred thirty-two advanced cancer patients were followed from the time they were enrolled until they died (an average of 4.4 months), and their caregivers' psychiatric illnesses and quality of life was assessed approximately six months later.

Of the patients, 123 reported in their baseline interviews at the beginning of the study that they had end-of-life discussions with their physicians. Those discussions were not associated with an increased incidence of major depressive disorders or with more worry, nor were there associations "between end-of-life discussions and patients' self reported sociodemographic characteristics, insurance status, cancer type, relationships with physicians, religiousness, or social support."

The EOL discussion patients were, however, "more likely to accept that their illness was terminal (52.9% vs. 28.7%), to prefer medical treatment focused on relieving pain and discomfort over life-extending therapies (85.4% vs. 70.0%), and to have completed a do-not-resuscitate order (63.0% vs. 28.5%)." They also were less likely to be on mechanical ventilators, to be resuscitated, or to be admitted to the ICU. They were "more likely to be enrolled in outpatient hospice for more than a week (65.6% vs. 44.5%)."

Those patients who had aggressive medical interventions had a worse quality of life in their final week, and that quality decreased as the number of aggressive therapies increased. In contrast, those patients who were enrolled in hospice had an improved quality of life the longer they were in hospice care, "except for patients who received less than a week of services."

Caregivers of patients who received aggressive treatments "were at higher risk for developing a major depressive disorder, experiencing regret, and feeling unprepared for the patient's death, compared with caregivers of patients who did not receive aggressive care. They also had worse quality of life outcomes, including overall quality of life, self-reported health, and increased role limitations."

The researchers report that there was a direct relationship between patients' quality of life near death and their caregivers' quality of life at follow-up. A high quality of life for the patient was associated with better outcomes for the caregiver, including "overall quality of life," "self-reported health," "physical functioning," "mental health," and "improvements in self-rated change in health." Those caregivers also were better prepared for the death of the patient, and expressed less regret at the follow-up interview.

The authors conclude by saying, "Given the adverse outcomes associated with not having end-of-life discussions, there appears to be a need to increase the frequency of these conversations. By acknowledging that death is near, patients, caregivers, and physicians can focus on clarifying patients' priorities and improving pain and symptom management." (JAMA, 2008;300 (14):1665-1673)

## American Public Health Association approves policy

The American Public Health Association has adopted a policy (10/08) supporting Oregon-style aid-in-dying laws, becoming the latest and largest medical organization to do so.

Submitted by Kathryn Tucker, Legal Affairs Director for Compassion & Choices, the group adopted the policy after two years of extended consideration, debate, discussion and some strong opposition. After fully and carefully considering all the arguments, APHA voted in favor of the policy by 58 to 42 percent.

The APHA carefully reviewed Oregon's *Death with Dignity Act*, and the evidence that it has caused no harm to patients, including those considered to be in vulnerable populations. The group also reviewed evidence that the *Death with Dignity Act* has significantly improved end-of-life care in Oregon and prevents covert, back-alley practices.

The organization becomes the fourth

national major medical association to examine Oregon's Death with Dignity experience and adopt policy supporting it.

Tucker applauded the public health leaders for supporting patient choice at the end of life.

"The adoption of policy supporting aid in dying by the APHA reflects a growing trend of support among mainstream medical and health policy organizations, recognizing the importance of this compassionate option," she said. "APHA's support for aid in dying should be influential as other states consider making this option legal."

In its published policy the APHA states that it "Supports allowing a mentally competent, terminally ill adult to obtain a prescription for medication that the person could self-administer to control the time, place, and manner of his or her impending death, where safeguards equivalent to those in the Oregon DDA are in place."

## Coombs Lee speaks at Mt. Sinai Medical Center

In May, Barbara Coombs Lee, President, Compassion & Choices, gave a lecture to a diverse audience at Mt. Sinai Medical Center on Honoring End of Life Choices: Policy and Practice to Reduce Harm. Barbara spoke about how too many patients are "tortured" at the end of life with life-sustaining and other treatments that neither improve quality or extend life but which cause unnecessary suffering. When patients have sufficient information to make informed choices, aggressive treatments are often not requested and people have better deaths. Barbara discussed end-of-life care in Oregon, where more open discussions take place, in part because of the Oregon Death with Dignity Act. End-of-life care has dramatically improved since the law became effective 11 years ago, with more people in hospice and being given better palliative care, making Oregon one of the best places to die, according to *Forbes Magazine*.

## C & C N Y board news

### Morellet resigns

After serving on the Compassion & Choices of New York board for almost a decade, including over 7 years as an outstanding president, Florent Morellet has resigned as president and from the board in order to pursue other interests. In his resignation note Florent said; "I am still deeply committed to the cause of Compassion and for all that has been done and continues to be done in New York and nationally to make dying better for millions of people. I have enjoyed working with all of you and thank you for being such good colleagues over the years." Florent was a wonderful leader for C&CNY and for the end-of-life movement. We are greatly indebted to him for his exemplary and inspirational leadership over the years.



Florent Morellet, past president of C&CNY

### Cuming and Clark join board

The good news is that we have two new board members, David Cuming and Elizabeth Clark, MD. David Cuming retired in 2006 after several years as CFO of Alleghany Corporation. He was previously employed by several major corporations including W.R. Grace, Monsanto and Philip Morris. Dr. Clark is an Associate Professor of medicine at Mt Sinai Medical Center. She has served as an internist and geriatrician at Metropolitan Hospital, as the Medical Director of the Outpatient Geriatrics Practice at Mt. Sinai Hospital and most recently as the Director of the Division of Geriatric Medicine at Lenox Hill Hospital.

### Gibbs elected C&C president

C&CNY board member Debbi Gibbs has been elected President of national C&C, after having served as Vice President the past two years. She has been on the C&CNY board for the past five years. She is the Director of Just Managing, a music agency, and has worked as an executive director in the broadcasting and entertainment industry.



Debbi Gibbs

### the inevitable...Continued from page 1

This is why C&C of NY has proposed legislation in New York, similar to a law that national C&C succeeded in having enacted in California. Our proposed law would require a physician, upon a determination that a patient is terminally ill, to offer the patient information and counseling regarding palliative care and end-of-life options. This will include but not be limited to: the range of options appropriate to the patient; the prognosis, risks and benefits of the various options; and the patient's legal rights to comprehensive pain and symptom management at the end of life.

The information and counseling may be provided orally or in writing. Where the patient lacks capacity to reasonably understand and make informed choices relating to palliative care, the physician shall provide information and counseling to a person with authority to make health care decisions for the patient.

We are very pleased that the chair of the Assembly Health Committee, Richard N. Gottfried and the chair of the Senate Health Committee, Thomas Duane, have introduced this legislation in their respective houses, A. 7617, S. 4498

We will keep you informed of the progress of this proposed legislation.

# Archives of Internal Medicine looks at end-of-life

Three articles in a recent *Archives of Internal Medicine* examine end-of-life issues. The first, "Abandonment at the End of Life From Patient, Caregiver, Nurse, and Physician Perspectives: Loss of Continuity and Lack of Closure," examines patients' feelings of abandonment by their physicians as they near the end of life. During three interviews (at time of enrollment in the study, 4-6 months later, and one year later), "participants spontaneously raised concerns about abandonment."

The study identified two themes:

- 1) "Before death, abandonment worries related to loss of continuity between patient and physician;" and
- 2) "At the time of death or after, feelings of abandonment resulted from lack of closure for patients and families." Physicians also identified lack of closure, but did not apparently consider this abandonment.

In conclusion, the authors say, "The professional value of nonabandonment at the end of life consists of 2 different elements:

- 1) providing continuity, of both expertise and the patient-physician relationship; and
- 2) facilitating closure of an important therapeutic relationship. Framing this professional value as continuity and closure could promote the development of interventions to improve this aspect of end-of-life care."

Writing about the study in *The New York Times*, Dr. Pauline Chen tells of her

interview with Dr. Anthony Back, lead author of the study. She quotes Dr. Back as saying, "We talk a lot about the professional value of non-abandonment. But we don't teach this value effectively. There are clearly doctors who aren't aware of the tremendous therapeutic value of their presence, even on the phone. And then I think there are doctors who are worried about how they will manage their emotions, so they keep things at arm's length."

Back recommends to patients that they say to their doctors, "I want to keep in contact with you and am wondering if I can talk to you on the phone once in a while before I get too sick to talk." Back says that he keeps in touch with his patients because "I get a lot out of it as a doctor. It's really nice for me to have one last conversation. It is an opportunity for me to ask how they are doing, to tell them how impressed I have been by the work they and their families have done. And people invariably say something about my work with them, so it is nourishing for me." (*Archives of Internal Medicine*, 2009;169(5):474-479; *The New York Times*, 3/12; *USA Today*, 3/10)

The second article, "Health Care Costs in the Last Week of Life: Associations With End-of-Life Conversations," reports on a study done by the National Institute of Mental Health and the National Cancer Institute. More than 600 patients participat-

ed and were interviewed at their enrollment in the study and followed until their deaths. Patients who reported EOL discussions had an average cost of care in the last week of life of \$1,876, which was 35.7% lower than those who did not have EOL discussions (\$2,917). The article also says that "higher costs were associated with worse quality of death."

**"Framing this professional value as continuity and closure could promote the development of interventions to improve this aspect of end-of-life care."**

The third article, "Racial and Ethnic Differences in End-of-Life Costs: Why Do Minorities Cost More Than Whites?" reports that the average cost to Medicare of care for white patients in the last six months of life is \$20,166, for blacks, \$26,704, and for Hispanics, \$31,702. White patients are the most frequent users of hospice (26%), followed by Hispanics (23%), then blacks (20%), but "racial and ethnic differences in end-of-life expenditures are affected only minimally."

The researchers say, "More than half of these cost differences are related to geographic, sociodemographic, and morbidity differences. Strikingly greater use of life-sustaining interventions accounts for most of the rest." (*Archives of Internal Medicine*, 2009;169(5):493-501)

## AMA adopts palliative sedation policy

Compassion & Choices has for years supported palliative sedation (also called terminal sedation) as an end-of-life option for dying patients. Now, the American Medical Association has adopted a new ethical policy saying that "Palliative sedation to unconsciousness is an important tool in the armamentarium of palliative medicine. For patients whose illnesses are terminal and end stage, palliative sedation to unconsciousness can ameliorate such intractable symptoms as delirium, pain, dyspnea, nausea, and vomiting. It is medically and ethically acceptable under specific, relatively rare circumstances."

The policy also says that "Physicians

should consult with a multidisciplinary team, including an expert in the field of palliative care, to ensure that symptom-specific treatments have been sufficiently employed and that palliative sedation to unconsciousness is now the most appropriate course of treatment...."

Further, the policy states that palliative sedation "must never be used to intentionally cause a patient's death." In her excellent article entitled *Terminal Sedation: Pulling the Sheet over Our Eyes*, Margaret P. Battin, (Hastings Center Report, September-October 2008) takes issue with the statement on intention and argues "The AMA report... attempts to infer intent from the pat-

tern of practice. 'One large dose' or 'rapidly accelerating doses' of morphine may signify a bad intention—seeking to cause death—whereas "repeated doses or continuous infusions" are benign. This is naive in the extreme. It's the slyest courtier who poisons the emperor gradually; what could equally well be inferred from repeated doses and continuous infusions is a clever attempt to cover one's tracks. Nor is it clear what counts as 'large doses' or other treatment measures in this simplistic dichotomy."

The National Hospice and Palliative Care Organization, The American Academy of Pain Medicine and the American Academy of Hospice and Palliative Medicine also support palliative sedation.



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