

connections

C & C N Y b o a r d n e w s

Board welcomes two new members

Compassion & Choices of New York welcomed two new board members this spring. **Peter Bienstock, Esq.** has had a long career in public interest law. Now in private practice, Peter has been the Executive Director, NYS Commission on Government Integrity. In the Office of NYS Attorney General Robert Abrams, he was Chief, Consumer Frauds, Deputy Chief, Public Advocacy Division and Chief, Civil Rights Bureau. He also worked at the Puerto Rican Legal Defense and Education Fund as a Staff Attorney and Litigation Director and the NY Civil Liberties Union Children's Rights Project.

Terry Perlin, PhD is Emeritus Professor of Interdisciplinary Studies and Research Fellow, Scripps Gerontology Center, at Miami University, Ohio. He has served as Professor of Psychiatry and Family Medicine at the University of Cincinnati College of Medicine, and as Visiting Professor of Medicine, University of California, San Francisco. He is the author of *Clinical Medical Ethics: Cases in Practice* (Little, Brown and Co.).

Leeman article published in *Psychosomatics*

Cavin Leeman, MD, a member of our Board of Directors, had an article published in *Psychosomatics – Distinguishing Among Irrational Suicide and Other Forms of Hastened Death: Implications for Clinical Practice (Psychosomatics 2009; 50:185–191)*

Dr. Leeman concludes his article by asserting that "Patients who wish to hasten their deaths may be responding to rational or irrational motives. Legal considerations aside, clinicians must be sensitive to patients' motivation, regardless of the specific method of hastening death that a patient selects. Death, of course, is irreversible, so it is important to delay action if time is needed to assess the patient's decision-making capacity, to gain understanding of the patient, to diagnose and treat clinical depression or other mental illness, and to relieve pain and other forms of suffering. All of these factors, which often are treatable, may influence the patient's decision. They should be considered even when the patient asks that treatment be withheld or withdrawn, a request that sometimes goes unexamined in modern medicine. On the other hand, it is important for psychiatrists to give up our traditional view that the wish to hasten death is always irrational, and that we have an absolute responsibility to do everything possible to thwart it. There are situations, fortunately infrequent, in which a patient's hastening his death, by his own choice and by any of the means discussed, is a rational act of last resort."



Dr. Cavin Leeman, C&CNY board member

year-end appeal: please contribute generously

As you know may know, we have not been sending out year-end mail solicitations in recent years. We hope that this newsletter gives you an idea of how diligently we are working to improve care at and expand choice at the end of life. Please send us a generous contribution so that we can continue all of our important work in New York, including our free high quality counseling and advocacy services. To make giving easier, please use the enclosed donation envelope.

Thank you for your continued support of C&CNY.

message

from the Executive Director
C&C's prominence expands

Our movement to improve care and expand choice at the end of life is progressing in many important ways on different fronts. With the passage of significant legislation, the Washington State ballot initiative, court victories, published articles and speaking engagements at many conferences and meetings, the prominence and influence of Compassion & Choices nationally and in New York continues to grow. New respected allies continue to join us. Some were featured speakers at the Dignity & Choices Symposium on End-of-Life Advocacy, sponsored by Compassion & Choices and held at the National Press Club in Washington, DC in October. I was proud to be at this first of what will be many successful events. I hope that those of you who missed this exciting and moving two day program will be able to attend future events.

Featuring two days of discussion, exploration and study, Dignity & Choices provided an opportunity to promote principles and practices that focus on patients. Physicians, social workers, nurses, attorneys and advocates for end-of-life choice filled the National Press Club to hear aspects of end-of-life care rarely discussed and illuminate the way forward.

Jacques d'Amboise can still dance, although not the jumps and pirouettes he once executed for George Balanchine. Electrifying the audience at the opening of the hugely successful Dignity & Choices symposium, he moved with remarkable elegance for a seventy-five year old, and showed even greater grace in discussing his wife Carolyn George's battle



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



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The Newsletter of Compassion & Choices of New York

Schwarz article published in American Journal of Nursing

"Stopping Eating and Drinking" by Judith Schwarz, RN, PhD, C&C of NY Patient Support Coordinator, was published in the *American Journal of Nursing*, September 2009 (Vol. 109, No. 9). The article explores the various issues involved in a patient's choice to stop eating and drinking. An excerpt follows:

"Anecdotal evidence and my own experience suggest that a growing number of frail, elderly people with multiple chronic illnesses who are able to make decisions are seeking ways to achieve, to quote a recent *New York Times* article, a "graceful exit" from a life that, as they see it, has simply gone on too long. Inevitably, a small proportion of these suffering, dying patients will ask their nurses for help in dying in order to escape their suffering.

"What Nurses Should Know"

"The decision to voluntarily stop eating and drinking differs from the loss of appetite or disinterest in food or drink that often accompanies the final stage of many illnesses. In this case, the patient is physically able to eat and drink but chooses not to; the intention is to hasten dying. Depending on the patient's physical condition, death usually occurs within one to three weeks of beginning a fast. The process requires a well-informed and determined patient who has family, friends, or others who can provide emotional and physical support; it's also crucial that the patient have access to clinical caregivers who can provide palliative or hospice support.

Patients and their loved ones who consider this option must understand in particular the importance of stopping all fluids (including ice chips) once the fast has begun so that death occurs within the one-to-three-week interval. Once oral intake stops, the patient usually remains wakeful and responsive for several days while weakening physically. This interval allows the patient to reflect on and perhaps reconsider the decision – and for loved ones to reminisce and prepare to say goodbye. Family members and other caregivers must be prepared for the possibility that the patient may decide to eat and drink again and support any decision the patient makes. If the patient wishes to resume eating or drinking, caregivers must provide food and fluids.

Also important is excellent oral care, particularly during the initial stage of the fast, when the patient is conscious and may be thirsty or have a dry mouth; using oral swabs and lip salve, rinsing the mouth and having the patient spit out fluids, or misting the back of the mouth with mouthwash or another fluid will help keep the mucous membranes moist and lessen discomfort. As dehydration progresses, the patient will become sleepier, eventually slipping into a coma before dying. Excellent physical care should continue, and loved ones may find comfort in providing it.

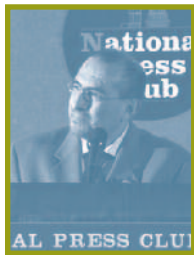
Occasionally, delirium or agitation may occur as death nears. Caregivers should be prepared for this possibility and know to contact a hospice nurse or palliative care clinician to provide palliative measures, including sedation, to ensure a peaceful death. When asked what it's like to care for hospice patients who voluntarily stop eating and drinking, nurses in one study said that this choice doesn't seem to cause unacceptable discomfort or distress and appears, in most cases, to facilitate a peaceful or "good" death".

prominence...Continued from page 1

with primary lateral sclerosis.

In the ballroom of the National Press Club, an audience of physicians, social workers, nurses, attorneys and advocates for end-of-life choice laughed as Jacques told stories from their unlikely courtship, and sat in hushed silence as he described Carolyn's determination to confront death on her own terms. With Jacques and her family beside her, she died at their home in Manhattan last February.

Dr. Elmer Huerta, former head of the National Cancer Society gave an insightful look at attitudes toward cancer, prevention and death in his home country of Peru, and here in the United States. The story of his years of discussions with his mother, and how he fought for her in her final days, illuminated the importance of honest discussions and patient advocacy.



In a meeting room down the hall, people gathered to hear from internist **Craig Bowron** what health care professionals can do to help patients and families be better prepared to deal with end-of-life issues. But Dr. Bowron was talking about bicycling. Dr.



Bowron, who works in St. Paul, Minnesota, remembered biking past lawns with sprinklers spraying in late autumn. "Water is not the problem here," he remembers thinking. "The sun has gone south, and all the water in the world is not going to turn these brown lawns green again." He recognized the parallel with his job as a hospitalist, "taking care of the threadworn elderly, those facing an eternal winter with no green in sight."

Barry Lynn, executive director of Americans United for Separation of Church and State, looked at the Religious Right movement, and how advocates must resist it to preserve autonomy. Lois Uttley of MergerWatch discussed the treatment restrictions imposed by hundreds of health care facilities



operated by religious entities. Dr. Timothy Quill of the University of Rochester School of Medicine, discussed the promise and perils of aggressive care and the complexities of end-of-life decision making.

Rev. Madison Shockley, pastor of the Pilgrim United Church of Christ in Carlsbad, California provided a religious perspective on the theology of compassion.

At a luncheon in the ballroom, *New York Times* health columnist **Jane Brody** accompanied her discussion with cartoons about death to show how humor can be an important weapon in breaking down our natural barriers to talking about the inevitable. She emphasized the importance of preparing an advance directive, and even more, the importance of communication: making sure your loved ones, doctor, attorney and everyone else know exactly what your end-of-life choices are.



Compassion & Choices President **Barbara Coombs Lee** joined Jane Brody at the podium to present her with the Hugh Gallagher Award on behalf of the national C&C Board. Jane Brody's passion,

dedication and perseverance exemplify the qualities embraced by Compassion & Choices. The Hugh Gallagher Award is given annually to a person who has been the most effective in bringing people, especially those of diverse age, race, religion, ethnicity, sexual orientation and persons with disabilities, to greater understanding of our issues and organization.

The two days of discussion, exploration and study were an important step toward establishing principles for patient-centered end-of-life care. As Coombs Lee said, in remarks at the closing of the conference, "Too often, the experience of patients gets lost in a flood of tests and treatments that often subvert any effort to navigate a fitting end to a well-lived life. Changing the focus from the disease to the person who has the disease would create radical change indeed."

Connecticut doctors, C&C file lawsuit

Two prominent Connecticut physicians, Dr. Gary Blick of Norwalk, and Dr. Ron Levine of Cos Cob, and Compassion & Choices filed a lawsuit in October to clarify the ability of mentally competent, terminally ill patients to obtain aid in dying from their physician if they find their dying process unbearable. The doctors are asking the court to declare that physicians who provide a prescription for medication to a mentally competent terminally ill patient, which the patient could consume to bring about a peaceful death, would not be subject to criminal prosecution under existing Connecticut law, which makes a crime of assisting another to "commit suicide." The choice of a dying patient for a peaceful death is no kind of "suicide," the physicians' lawsuit asserts, and the physician does not assist such a patient in "committing suicide." Jamie Mills and Daniel Krisch, both Hartford attorneys, and Compassion & Choices Legal Director Kathryn Tucker, a Connecticut native, represent the physicians.



Dr. Gary Blick and Kathryn Tucker, Esq.

study on mental health effects released

According to an Oregon Health and Science University study, "Comparing family members of those who requested aid in dying to those who did not revealed no differences in primary mental health outcomes of depression, grief, or mental health services use. Family members of Oregonians who requested aid in dying felt more prepared and accepting of the death than comparison family members. In summary, pursuit of aid in dying does not have negative effects on surviving family members and may be associated with greater preparation and acceptance of death." The abstract can be viewed online at [http://www.jpsmjournal.com/article/S0885-3924\(09\)00707-6/abstract](http://www.jpsmjournal.com/article/S0885-3924(09)00707-6/abstract). (*Journal of Pain and Symptom Management Online*, 2009).

Leven on radio in New York and Great Britain

Executive Director David Leven spoke about aid in dying in extensive interviews on several radio programs including on the Brian Lehrer Show, on WNYC, the local NPR station in NYC, the BBC and on WVOX radio in Westchester County.

Leven published on *Family Health Care Decisions Act* in *The Journal News*

July 25, 2009

Assembly must pass the *Family Health Care Decisions Act*

By David C. Leven

Unlike virtually every other state, New York has no law allowing a family member, partner or trusted friend to act as a surrogate medical decision-maker on behalf of a patient who has become incapacitated without leaving specific instructions about medical care. This is unacceptable as the vast majority of our citizens have not completed an advance directive.

Legislation termed the *Family Health Care Decisions Act* would correct this problem by allowing loved ones to make health decisions for those who have lost the ability to make them. Tragically, to the detriment of dying patients, in particular, and loved ones, this bill has been languishing in the New York Legislature for more than 15 years. The Senate, which is to be congratulated, passed the bill this year; it is now time for the Assembly to act. It has passed a bill in the past, but not in its current form. This should be a priority for local legislators, seven of whom are sponsoring the Assembly bill, A. 7729C.

More than 150,000 people die in New York yearly, including more than 7,000 in Westchester County. Too many die bad deaths, too many suffer needlessly, often because they are kept alive in situations where health-care professionals believe they have no other legal choice. Imagine that a devastating auto accident has left you completely incapacitated, unable to talk to your doctors about life-and-death medical decisions. You don't have a health-care proxy or a living will spelling out your wishes. But, no matter, because a loved one could step in and speak for you, right? Not in New York. This is the problem.

Or, imagine that your 105-year-old mother, who suffered a stroke five years earlier, from which she has never recovered, is suffering from severe dementia and is receiving artificial nutrition and hydration. She has not communicated in years and does not appear to recognize you or anyone else and seems, by facial expression, to be unhappy. She now has pneumonia. Do you want mom to be given antibiotics? If your mom has not communicated her wishes in an advance directive or if you cannot prove her specific wishes by clear and convincing evidence (a very high legal standard), your mom may well be given the antibiotics.

Regardless of what you think your mom would want or what you would want for her in accordance with her values and in her best interest, health-care professionals are the only ones who can legally decide what now happens with mom. This is not the way decisions should be made.

Simply stated, health-care decisions for patients who can no longer make them should be made by loved ones even in the absence of explicit directions, as almost every state but New York permits. For that to happen in New York, enactment of the *Family Health Care Decisions Act* is necessary.

The legislation has numerous safeguards. The bill enables family members or other close loved ones to make health-care decisions for you only if an attending physician and a second health-care professional determine that you lack capacity to decide for yourself. Decisions must be consistent with your wishes (including your religious and moral beliefs) or, if your wishes are not reasonably known, decisions must be made in your best interest. Life-sustaining treatment decisions can be refused only in limited situations, when you are terminally ill or permanently unconscious, or you have an irreversible or incurable condition and treatment would involve such suffering or other burden that it would be deemed excessively burdensome under the circumstances.

Not surprisingly, this bill has the support of almost all major medical groups across the state and numerous civic and community organizations. Who could be opposed to us making health decisions for our incapacitated loved ones?

Passage of the *Family Health Care Decisions Act* is long overdue. Please urge your Assembly member to help to ensure that the Assembly passes this bill before the end of the year.

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legislation moving toward enactment

We are on the brink of getting important legislation enacted in New York. Three bills initiated by Compassion & Choices of New York were passed by the New York State Assembly. They most likely would also have been passed by the New York State Senate were it not for the unusual dysfunction this year when for weeks only one house of the legislature was in session but not both. Our Palliative Care Information Act, to ensure that dying patients receive complete information of their palliative and end-of-life care options, unanimously passed in the Assembly. Our Safe Harbor bill, to protect physicians who effectively prescribe pain medications, and our bill to require only one witness to the signing of a health care proxy also were passed by the Assembly. We are confident that these bills will be enacted next year.