



Compassion in Dying of New York dba
Compassion & Choices
 of New York

Summer 2005 Issue

PMB 2010
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celebrate!

In May we celebrated the unification of Compassion in Dying and End of Life Choices, creating a new powerful organization, Compassion & Choices. We shared the celebration with some 400 friends, new and old.

- We honored those in the media and those who have written on death and dying, for their important work in expanding awareness and broadening our knowledge about choice in dying and having a peaceful and humane death.
- We conducted a very successful art auction at which pieces donated by some of our most celebrated contemporary artists generated significant funds that will further our work.
- We were privileged to have Diane von Furstenberg, who donated her studio for the celebration, co-chair the event with C & C of NY President Florent Morellet and to have Isaac Mizrahi and Ally Sheedy host the celebration. All of them brought us warmth in words and thoughts from their hearts.
- We celebrated with gusto and verve, with fabulous food and drink, all donated to C & C of NY.

Yes, we raised money, almost \$150,000! Equally important, we introduced our organization and its mission to improve care and expand choice at the end of life to a greater number of concerned New Yorkers.



Marsha Temple, Compassion & Choices Co-CEO and Barbara Coombs Lee, Compassion & Choices Co-CEO.



Left to right: Florent Morellet, C & C of NY Board President & Co-Chair; Debbi Gibbs, Benefit Chair; Isaac Mizrahi, Co-host; Ally Sheedy, Co-host; and David Leven.

compassion & choices collaborates with guardianship project

Compassion and Choices recently engaged in an interesting collaboration with members of the Guardianship Project, as a consequence of a fortuitous common source of funding (The New York Community Trust). The Guardianship Project provides guardianship services for people who have been judged to be incapacitated by a court. Members of this project, staffed by attorneys and social workers, work closely with advocacy organization to connect people they serve to appropriate service providers in their communities. The project's director, an attorney, and Judith Schwarz, C & C Patient Support Coordinator, worked to improve end-of-life care for a decisionally incapacitated 91 year old gentleman recently hospitalized with many chronic and several acute medical problems. His only 'family' was a nephew in California who did not want his uncle to suffer.

Unfortunately, the patient had not completed an advance medical directive before becoming incompetent, and thus was being aggressively treated with many intrusive and painful interventions that seemed to merely prolong his dying. Working together over several weeks, we were able to arrange for a consulting physician in palliative care to examine the patient and assume clinical responsibility for his care so that he finally received appropriate pain management and comfort care. He was able to die, peacefully and without pain, very much to the relief of his nephew.

message from the executive director

as you may know, we are now Compassion & Choices of New York, *an affiliate of Compassion & Choices*. The unified Compassion & Choices is the nation's leading organization seeking to improve end of life care, expand choices at the end of life, and provide high quality patient services. We are proud to be connected with the new Compassion & Choices. We hope that you will join Compassion & Choices, if you are not already a member, and that you will also continue to support Compassion & Choices of New York. Our Celebration of the new, unified organization, described below, was a huge success, financially and otherwise. However, to survive locally and to be able to provide the free, quality services that we do, we rely primarily on individual contributions from people like you; it is still very difficult to find foundations that will fund what is (although it should not be) a controversial organization like ours. If you did not contribute to the Celebration and have not made a gift this year, please make a generous donation in the enclosed envelope.

Fueled by the tragic Terry Schiavo case, death and dying issues dominated the news for weeks this spring. It forced many of us to think about and discuss these issues—something most of us avoid doing at all or until it is too late, seriously disadvantaging ourselves and our loved ones. True, the Schiavo matter was highly unusual in many ways. Nevertheless, it made us realize that while health care decision-making is not always easy, what decisions are made and who makes them are highly important. And, hopefully, this tragedy taught us a most important lesson: if we want our own health care wishes to be honored, we had better talk with someone we trust who is willing to make health care decisions for us if we lose decision making capacity and must follow up that discussion by completing a health care proxy appointing that person as our agent. Doing this assures that our values and wishes will be known by our agent so that if ever we do lose decision-making capacity we will have a voice that can speak for us and advocate on our behalf. I wish each of you had a health care proxy but, given



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

"...we rely primarily on individual contributions from people like you; it is still very difficult to find foundations that will fund what is (although it should not be) a controversial organization like ours."

the fact that less than 25% of our citizens do, I am sure that many of you still do not. The time to complete one is now, while you are still healthy. And if you have children, grandchildren, nieces or nephews, 18 or over, please encourage them to fill out this simple form. Each of the prominent cases on the removal of life support involved young women in their 20s. The Schiavo and Cruzan cases went to the U.S. Supreme Court; the Quinlan case reached the New Jersey Supreme Court before her parents were permitted to have life support removed from their daughter.

Below is an update on the Family Health Care Decisions Act, which would enable surrogates to make health care decisions for loved ones who lose capacity and who have not designated a health care agent. As important as this legislation is, you should still have an appointed agent. Why? Because your surrogate decision maker may not know your wishes and may make decisions for you contrary to your wishes even if acting in good faith.

If you do not have a health care proxy, we will be happy to provide you with the appropriate form and will discuss it with you if you wish. We will also provide you with a living will, a document which should be completed if you do not have a trusted person whom you can appoint as your health care agent. Call us at 212-561-9175.



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family health care decisions act moves closer to passage

An excellent editorial in *The New York Times* (May 29) supports passage of the Family Health Care Decisions Act, a bill that Compassion & Choices of New York has been instrumental in moving forward. As the editorial notes, the “Act would fill a glaring gap in New York State law. Under current law, no one—not even a spouse, parent or other close family member—has the authority to refuse life-sustaining treatment for an incapacitated patient, unless that patient has either signed a health care proxy or provided “clear and convincing evidence” of his or her wishes in some other fashion.

A 1988 ruling by the state’s highest court, the Court of Appeals, made New York one of only two states (the other is Missouri) where courts have specifically held that family members cannot make these decisions. Indeed, without a health care proxy, family members cannot review medical records or admit an incapacitated loved one into a hospice program. Since about 75 percent of New Yorkers have not signed health care proxies or living wills, this is a big problem.”

Passage of the bill would allow loved ones to make health care decisions for those who lose capacity; such decisions should be in accordance with the patient’s wishes, to the extent they can be determined, or otherwise in the patient’s best interests.

Differences exist between the New York State Senate and Assembly bills and these should be resolved. As the editorial correctly asserts, “it is high time for action.”

schiago case presents many media opportunities

Compassion & Choices was prominent in the national and local media responding to requests for interviews and comments on the Schiavo case.

Judy Schwarz, RN, PhD, patient support coordinator for C & C of New York, and David Leven were on the WBAI radio show *Health Styles*, for a one-hour program on Schiavo and advance directives.

Board President Florent Morellet had an article published in *The Daily News* on the need for Health Care Proxies and Living Wills.

Board member Peter Rogatz, MD, wrote a column on advance directives for *Networking* (a monthly newspaper/magazine geared to women executives on Long Island). He was also quoted in an article in *Newsday*.

David was on radio and television and also had letters and an op-ed in the print media. In most appearances he spoke about importance of having a health care proxy and honoring a person’s health care wishes. He also spoke about the inappropriate intervention of Congress in the Schiavo case. In the New York media, David emphasized the need to pass the Family Health Care Decisions Act.

Media appearances included the Fox Cable News program, *The Big Story*, Regional News Network Television (RNN), by phone, WCBS TV local (NYC) WCBS 880 radio, Alan Colmes Fox radio talk show, WVOX Westchester radio WILN radio, a Wilmington Delaware station. David had letters to the editor published in the *Albany Times Union* and in *The Journal News*, a Westchester, Putnam Rockland paper, and had an op-ed piece published in *The Journal News* on the importance of health care proxies, resulting in over 30 requests for proxy forms.

o u t r e a c h

patient support team grows to 12

We are fortunate to have recruited several new patient support volunteers who bring a variety of skills and experiences to our patient support team. Karen Doty, John Erman and Judy Friedman are new volunteers. We also now have two former Caring Friends, Carolyn Monro and Anita DeMartino on the team. The patient support team meets monthly to discuss individual patients to ensure that they are getting the best possible counseling from our staff and volunteers and are receiving appropriate end of life care.

meetings with seniors

David Leven met with the AARP Westchester chapter to discuss end of life issues. He also made a presentation to the Brooklyn Chapter of the Older Women’s League, after which the Chapter voted to support the Family Health Care Decisions Act and the pain legislation that C & C had initiated. In March David spoke at a meeting of the Larchmont Senior Citizens. Soon after Terry Schiavo died, David met with Scarsdale seniors and, although many attendees did have health care proxies, virtually all of those who did not have proxies requested the forms. In May, David attended the Salute to Seniors Expo at the Westchester County Center where he handed out about 200 packets of materials on C & C and health care proxies.

on the airwaves: physician assisted dying

C & C of NY Board President Florent Morellet and David Leven were on Regional News Network, RNN, discussing the need for a physician assisted dying law in New York, modeled after the Oregon law which has worked extraordinarily well. David was on ABC Radio’s “Live from 125” program hosted by Ellis Henican, which runs in 60 major markets around the country as well as on SIRIUS and XM satellite radio speaking about the lessons of the Schiavo case and why the Oregon physician assisted dying law should be replicated nationwide.



educating health care professionals

Judy Schwarz and David Leven have been guest lecturers at a number of nursing school classes, Judy at NYU Division of Nursing and David at College of New Rochelle School of Nursing. Judy will be teaching in the fall at Hunter Bellevue School of Nursing. We have been able to convey a great deal of useful and practical information as advocates for the terminally ill, about the many problems they encounter at life's end and how nurses, too, can be advocates for their patients. These students, many already working in hospital and other health care settings, now also know that they can refer patients to us.

David Leven spoke at a meeting of the Social Issues Division of New York State Psychological Association and Psychologists for Social Responsibility. He also spoke to

a class of 22 PhD Psychology students at Seton Hall University on physician-assisted dying and on the pain legislation. At a meeting of the Westchester End of Life Coalition, David was on a panel with Assemblywoman Amy Paulin speaking on end of life and health legislation in NYS including the pain bills, Family Health Care Decisions Act, medical marijuana and physician assisted dying.

In April, Judy gave lectures and talked with students and faculty at Sonoma State University. Her audiences included nursing faculty, under-graduate sociology students in a class on Death & Dying and masters nursing students in ethics. She spoke about the Oregon Death With Dignity law, plans to replicate the law in California and nursing research regarding requests for assistance in dying.

pain bills reintroduced

Proposed legislation, introduced at the urging of Compassion & Choices, would require pain management courses in medical schools; require continuing medical education courses for physicians, pharmacists and nurses in pain management; protect physicians from disciplinary or state criminal sanction for treating pain effectively if the physician is practicing in accordance with a nationally recognized health care standard; and make clear that failure to treat pain properly could result in professional discipline.

Bill A.7640 "Includes education and training in pain management and end-of-life care under the requirements of physician education." This bill would require medical school curricula to include classes on appropriate treatment of pain. Status: In committee in the assembly; no Senate companion bill introduced to date.

Bill A.7642 (and its companion bill S.5017) "Requires clinical education in pain management and establishes an advisory committee on pain management education." This bill would mandate continuing education specific to treatment of pain. Status: A 7642, referred from Assembly Health Committee to Codes Committee;

Senate companion bill, S. 5017, in Senate Health Committee.

Bill A.7643 and its companion bill S.5016 are safe harbor bills. The bills provide protection from disciplinary action for physicians who aggressively treat their patients' pain. The bills also provide that a physician may be held accountable for the inadequate treatment of pain. Status: A. 7643 referred from Assembly Health Committee to Assembly floor—laid aside on 5/23; Senate companion bill, S.5016 in Senate Health Committee.

After careful consultation with prominent pain management specialists and educators, another bill has been drafted, the **Palliative Care Education and Training Act**, to improve pain management and palliative care by:

- Providing up to 14 grants at not more than \$175,000 to medical schools to improve their educational and training efforts in pain and palliative care;
- Providing no more than 25 grants up to \$100,000 for palliative care residencies;
- Designating Centers for Pain Management Excellence, designed to provide specialized palliative care,

Compassion & Choices of New York Welcomes New Board Members

Lauren Shaiova, MD and Lynne Kwalwasser, PhD have joined the Compassion & Choices of New York Board of Directors. Dr. Shaiova is an attending physician at Beth Israel Medical Center Department of Pain Medicine and Palliative Care where she treats all chronic pain syndromes as well as cancer pain, HIV pain and sickle cell pain. Dr. Kwalwasser is a certified Psychologist with a private practice as a Psychoanalyst and Individual, Family and Group Psychotherapist.

treatment, education, and related services for patients suffering from acute or chronic pain, for treating pain;

- Establishing a Pain Management Practitioner Resource Center for health care professionals, to act as a source of technical information for practitioners on the latest pain management strategies, therapies and medications, utilizing both online and telephone-based systems to provide guidance to practitioners faced with specific pain management issues beyond their expertise.