

connections

legislation 2011: moving forward to improve care & expand choices

The enactment of the *Palliative Care Information Act* was our third legislative success in the past 4 years (the others being *Palliative Care Education and Training Act* and our *Advance Care Planning Education bill*).

This year our bill to require only one witness to the signing of a health care proxy passed both houses of the state legislature but was vetoed by the governor partly because of a concern about forgery, which we believe did not justify a veto. Assemblymember Linda Rosenthal will re-introduce the bill. Our safe harbor bill has passed the Assembly but not the Senate and we are hopeful that it will be enacted next year. This bill would provide some protection for a physician who, although treating his/her patient appropriately with opioid drugs, might be unfairly accused of over-prescribing. We also hope to secure enactment of bills to be introduced, that would accomplish the following:

1. allow for a space on the back of a driver's license for health care proxy contact information;
2. hold institutions and health care professionals liable who do not comply with health care decisions of patients, health care agents or surrogates;
3. require earlier notice to patients, health care agents and surrogates by institutions that refuse to honor decisions to withhold or withdraw life sustaining treatment;
4. require that information on health care proxies be provided to applicants for certain state benefits.

And we are reviewing the possibility of having a bill introduced to require continuing education for health care professionals on pain management, palliative and end of life care and another bill to provide protection to health care professionals who provide care to relieve suffering.



Assemblymember
Linda B. Rosenthal

from our patients & families...

"Recently, I called Compassion & Choices of New York with a desperate plea for help. Not only did all of you involved respond immediately, you continue to do so with great kindness, Compassion, knowledge and professionalism. With much appreciation. My sincere thanks."

– a C&CNY patient

"Compassion and Choices care and support at that very difficult time was very much appreciated by all of us... I also want to thank you for your kindness in talking with me. It's wonderful to know there is help and support available from good people."

"We are grateful to Judy... for her ever-available compassionate and straight-forward mentoring of my Mom and me. I felt as though Judy had known us all our lives – every conversation was spot-on, as if she knew us all enough to know what we needed to hear emotionally and realistically..."

– a C&CNY patient family member

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 hard 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. Thank you.

– David Leven, C&CNY staff and volunteers



major victory for patients at end of life

Compassion & Choices of New York helped establish a major patient's rights victory in New York State with the signing of the *Palliative Care Information Act (PCIA)* in August. Terminally ill patients will now have a clearly defined right to receive information and counseling about their palliative care and end-of-life options, including hospice. We initiated the bill, with help from national Compassion & Choices, and were able to secure sponsorship of the bill by the chairs of the assembly and senate health committees. We also played an important role in urging Governor Paterson to sign the bill, by presenting numerous studies, including very recent ones, demonstrating the need for this legislation, right up until the final day.

The law will enable patients to make informed treatment decisions during the final months of their lives. The law states:

If a patient is diagnosed with a terminal illness or condition, the patient's attending health care practitioner shall offer to provide the patient with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including but not 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.

Additionally:

- The obligation to provide such information and counseling can be fulfilled by the attending physician or nurse practitioner or by referral or transfer to another appropriate health care practitioner.
- Information can be provided verbally, or in a written document that the Department of Health is authorized to produce.
- Information and counseling would not have to be provided to a patient who does not want it.
- Information and counseling shall be provided to a person with authority to make health care decisions for the patient if the patient lacks decision making capacity. This can be a health care agent or surrogate.

Although the need for, importance and benefits of the *PCIA* are clear, disappointingly, the Medical Society of the State of New York (MSSNY) opposed the bill, raising several objections that are copied below, with our responses to them.

MSSNY Claim: "To mandate a discussion regarding end of life care, before the patient is ready, intrudes unnecessarily upon the physician-patient relationship."

The Facts: This is contrary to what the bill provides. Under the bill, as mentioned above, a physician is only required to have the conversation **if the patient wants to**. If the patient is not prepared to have the conversation the physician has no obligation to do so.

MSSNY Claim: "This bill establishes a legislatively designed standard of care and, shockingly, it mandates physician adherence to it regardless of what the patient's physician believes to be most appropriate for his or her patient."

The Facts: This sentence is inaccurate in two ways. First, the bill in no way, shape, or form speaks to a standard of care. All it does require doctors, upon the consent of their patients, to share with their patients the options that are available to them. What course their care then takes is up to the patient and their doctor. The bill says nothing

Continued on page 2

message

from the Executive Director

NY's palliative care information act

New York's *Palliative Care Information Act*, which was enacted largely because of the work of Compassion & Choices of New York, is described at greater length in this newsletter. It empowers terminally ill patients to make informed decisions about their palliative care and end-of-life options, after receiving information and counseling by physicians or nurse practitioners. Despite the well-established right of patients generally to be provided with information sufficient for them to make informed decisions about their treatment, this new law was desperately needed for many critically important reasons.



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

First, at the end of life, many physicians do not have discussions with their patients about diagnosis, prognosis and treatment options and, even when they do, such discussions are often not adequate. One recent study involving 332 advanced cancer patients who were followed from the time they were enrolled until they died (an average of 4.4 months) found that only 123 of those patients had end-of-life discussions with their physicians.

Secondly, the vast majority of dying patients want to know their diagnosis and prognosis. In one study of 214 persons aged 60 and older with a limited life expectancy secondary to cancer, congestive heart failure, or chronic obstructive pulmonary disease, 83% of those believing they had 1 year or less to live wanted to discuss prognosis. And, in a recent survey of patients with 3 different forms of cancer, 95% of them wanted their oncologist to be honest about their expected survival.

Thirdly, the lack of physician-patient communication is one reason why hospice referrals occur so near death or not at all. In

Continued on page 2



New York Governor David Paterson

new board president of C&CNY

Terry M. Perlin, PhD became the President of Compassion & Choices of New York this year. Dr. Perlin is a Consultant in Medical ethics. He is also Emeritus Professor of Interdisciplinary Studies and Research Fellow, Scripps Gerontology Center, having been a faculty member at Miami University from 1975-2009. He has held teaching and research positions at Williams College, Massachusetts and at University of Cincinnati College of Medicine; he recently served as Visiting Professor, General Internal Medicine at University of California, San Francisco. Perlin is the author of *Clinical Medical Ethics: Cases in Practice* (Little, Brown and Co.). He serves as ethics consultant to the American Association of Blood Banks. The board and staff welcome Terry. We also express deep appreciation to Peter Rogatz, MD for dedicated service as Acting President.



Dr. Terry Perlin

NY's palliative care information act...Continued from page 1

New York State, the median length of stay in hospice is 17 to 19 days, with 33% or patients only enrolled for 8 days or less and another 33% enrolled for 31 days or less in 2007, the last year for which figures are available.

Most importantly, when discussions take place between physicians and their dying patients, quality of life is improved, decisions are made for less aggressive interventions, lives are extended, patient's wishes are more likely to be respected, hospice referrals occur sooner and cost savings result.

End-of-life (EOL) discussions that patients had with their physicians, according to one study, 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." However, The EOL discussion patients were more likely to accept that their illness was terminal, to prefer medical treatment focused on relieving pain and discomfort over life-extending therapies, and to have completed a do-not-resuscitate order. They also were less likely to be on mechanical ventilators, to be subjected to the often futile and invariable severe trauma of cardio-pulmonary resuscitation, or to be admitted to an ICU. And they were more likely to be enrolled in outpatient hospice for more than a week.

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 ther-

apies increased. In contrast, those patients who were enrolled in hospice for more than a week had an improved quality of life the longer they were in hospice care.

Another recent study found that patients with terminal lung cancer who began receiving palliative care immediately upon diagnosis not only were happier, more mobile and in less pain as the end neared – but they also lived nearly three months longer.

A study on patients with cancer found that they are more likely to receive EOL care that is consistent with their preferences when they have had the opportunity to discuss their wishes for EOL care with a physician.



C&CNY supporter Linda Rodgers Emory and David Leven celebrating the passage of the PCIA.

Finally, according to a 2009 study, patients with advanced cancer who reported having EOL conversations with physicians (only 31% of the patients had such discussions) had significantly lower health care costs in their final week of life. Those costs were \$1,876 for patients who reported EOL discussions compared with \$2,917 for patients who did not, a cost difference of \$1,041 (35.7% lower among patients who

victory...Continued from page 1

about any treatment options, nor does it say that a patient's care must follow any particular path. This objection has no basis in fact.

Second, the bill clearly gives patients the opportunity to receive information and counseling **only if they want it**. The bill clearly states that what must be provided is "information and counseling regarding palliative care and end-of-life options **appropriate** to the patient" (emphasis added). So MSSNY's assertion that the bill would require a physician to do anything that is contrary to his/her judgment of what is appropriate is inaccurate.

MSSNY Claim: "To require a physician to offer to have the discussion is in effect a mandate to have the discussion."

The Facts: Whether a conversation takes place, or not, **is controlled by the patient**. To offer the discussion is not, as suggested

Continued on page 3

reported EOL discussions). Higher costs were associated with worse quality of death. This study also found that patients who had EOL discussions with their physicians "were more likely to receive outpatient hospice care and be referred to hospice earlier."

There was clearly a profound need for enactment of the Palliative Care Information Act. We expect this new law to have many positive benefits for both dying patients and the health care profession throughout New York State.

If you think that you or a loved one (especially if you are the health care agent for that person) may be terminally ill, you should consider initiating a discussion with your physician or the physician of your loved one and inquire about current diagnosis, and prognosis. If it your physician confirms that you or your loved one is terminally ill then you should insist, if you want it, on receiving information and counseling on your palliative care and end-of-life options and the risks and benefits of those options so that you can make informed decisions about your treatment and care. If any issues arise regarding receiving or not receiving information and counseling, please contact Judith Schwarz, RN, PhD, C&CNY Clinical Coordinator for help at 212-561-9175. We want to make sure that physicians know about and are complying with the law.

New York's *Palliative Care Information Act* is a model for the nation.

victory...Continued from page 2

by MSSNY, a mandate to have the discussion. The patient is in control.

MSSNY Claim: "Furthermore, the bill is completely unnecessary because I already have the professional responsibility (and legal responsibility under existing informed consent legal provisions) to provide information including prognosis and treatment options for all medical problems."

The Facts: This is quite a revealing statement: in essence, MSSNY admits that providing the information specified in the bill is consistent with good medical practice. It would thus appear that MSSNY's real objection is to having the law specifically require doctors to do something. In other words, their objection is philosophical, not substantive. Compassion & Choices submits that MSSNY's philosophical objection to the law directing doctors to do things is not a sound basis for public health policy. Rather, the interests of patients should guide public policy.

For the record, existing law states that patients have a right to: "Receive complete information about your diagnosis, treatment and prognosis..." 10NYCRR, 405.7(c)(8) and to: "Receive all the information that you need to give informed consent for any proposed procedure or treatment. This information shall include the possible risks and benefits of the procedure or treatment", 10NYCRR, 405.7(c)(9). This bill simply enhances these broad rights to include the specific right to receive information about available options when a patient is diagnosed with a terminal illness.

MSSNY Claim: "As a physician, I view this measure as intrusive into the clinical practice of medicine in ways that could well be seriously detrimental to the patient's interest."

The Facts: It's difficult to comprehend how this bill, which merely empowers patients by providing them with information (if they decide they want it), is somehow detrimental to them. Moreover, the *Family Health Care Decisions Act (FHCDA)*, which was supported by the MSSNY, specifically states that: "the surrogate shall have the right to receive medical information and medical records necessary to make informed decisions about the patient's health care. Health care providers shall provide and the surrogate shall seek information necessary to make an informed decision, including information about the patient's diagnosis, prognosis, the nature and consequences of proposed health care, and the benefits and risks of and alternative to proposed health

o u t r e a c h

a discussion about voluntarily stopping eating and drinking

By Judith Schwarz, RN, PhD, C&CNY Clinical Coordinator

On the evening of October 5th, 2010, we had an over-flow crowd who came to All Souls Unitarian Church on Lexington Avenue to hear a talk about the end of life option of Voluntarily Stopping Eating and Drinking (VSED). More than 70 people sat in the pews, in the isle and on the stage, while others stood at the back of the Small Chapel. Another dozen or so called with regrets that they couldn't attend and asked that printed material be mailed to them about this option. It was quite a remarkable night for a number of reasons. Most of the people in attendance had never before attended one of our information-sharing evenings, just about everyone stayed for the full two hours, and there were many interesting questions asked.

I've thought carefully about why there is so much interest in VSED. Here in New York and New Jersey it is not unusual for patients to choose this means of controlling the timing and circumstances of their dying. There are several possible reasons for this heightened interest in VSED; first it's a legal option that permits 'natural' dying, in the privacy and comfort of one's own home, surrounded by familiar objects and people. Second, families or close friends are able to participate in caring for their loved ones, as the process of slipping away occurs gradually over a period of days, generally not exceeding two weeks. Physicians and hospice providers usually will support this choice, and it is the patient who gets to decide – whether to initiate fasting and whether to continue to do so. No medical permission is required. VSED seems to hold particular appeal for elderly folk who have retained cognitive capacity [and hence can decide about this option] but suffer from multiple chronic ailments that leave them feeling miserable and uncomfortable – if not in pain. They are frequently isolated in apartments or homes they can no longer leave without assistance, and seem often to have lost the ability to read or watch TV, to hear music or to pursue other previously enjoyable pastimes. For questions, feel free to call me, Judith Schwartz, at 212-561-9175.



Judith Schwarz

Leven educating health care professionals & students

David Leven gave a plenary talk before about 175 people at the **Jewish Home Life Care Palliative Care Conference in Manhattan**. The presentation on health care decision making, particularly at the end of life, focused on patient autonomy and rights and David spoke specifically about Health Care Proxies, the *Family Health Care Decisions Act (FHCDA)*, *Palliative Care Information Act (PCIA)* and Medical Orders for Life Sustaining Treatment (MOLST). At **Jewish Home Life Care Sarah Neuman Center in Westchester**, David was on a panel speaking to health care professionals on Health Care Proxies, *FHCDA*, *PCIA* and MOLST. At the **State Society on Aging of New York State Conference**, David was on a panel on these same topics. He also gave two presentations on MOLST as part of a panel for **Senior Law Day at Westchester County Center**. David lectured to **Pace University** nursing students and to **Fordham Graduate School of Social Service** students on end-of-life decision making and choices.

care." *Public Health Law*, Article 29 CC, section 2994-d3(c). This requirement is similar to and consistent with the provision in the *Palliative Care Information Act (PCIA)*, which ensures that information will be provided timely, with the additional important requirement that at the end of life counseling will also be provided if desired by the patient or surrogate.

We were very pleased to have the support of the Hospice and Palliative Care

Association of New York State the New York State Association of Health Care Providers and Westchester End-of-Life Coalition, among others as well as the support of respected palliative care physicians.

We now are working with the NYS Department of Health, the Hospice and Palliative Care Association of New York State and others to ensure that the law is implemented effectively when it takes effect in February.