

# connections

## consumers of Catholic healthcare, be aware

Last November, with little fanfare, the United States Conference of Catholic Bishops revised its directive to Catholic health care institutions regarding feeding tubes. The revised directive 58 is clearly intended to impose a conservative doctrine at Catholic-affiliated hospitals, nursing homes and other facilities. Standing in opposition to the preferences stated by millions of Americans, and contradicting the emerging consensus in medical practice and bioethics, the Bishops have declared that artificial nutrition and hydration (ANH) is, in principle, obligatory for anyone in a permanent coma from stroke or trauma, in persistent vegetative state or with advanced dementia, having lost the ability to eat along with other sentient activity. This is a very strict standard. According to the directive, "Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be "excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed".

Compassion & Choices is engaged in efforts inform people on how this could limit the healthcare choices of millions of Americans, regardless of their religion, the preferences expressed in their advance directive or by family members. Approximately 30% of Americans receive healthcare or reside in Catholic institutions, and this edict could affect any of them. Significantly, in many parts of the country, Catholic institutions are the only ones available. A little-known but far-reaching aspect of the Church's organizational structure requires every hospital, nursing home, assisted living center, etc., with a Catholic charter, to abide by a set of rules called "Ethical and Religious Directives for Catholic Health Care Services." The 72 directives itemize exactly how the services provided must conform to Catholic doctrine

How many families, making difficult decisions under the stress of anticipated loss, will understand that their providers reject their choice? How many will have to choose between seeking a difficult transfer to another facility and rejecting the values and wishes of loved ones who can no longer speak for themselves? Compassion & Choices is working with stakeholders from across the nation to develop a long-term strategy. Whether the attempt to interfere comes from medical personnel, governments or religious institutions, our goal is to defend individual choice and personal autonomy in end-of-life care decisions.

**To protect patients from unwanted treatment in Catholic and other religious hospitals, Compassion & Choices has devised a new sectarian advance directive. It may be downloaded by going to:**

**<http://www.compassionandchoices.org/documents/SectarianHealthCareDirective.pdf>**

## in the media

David Leven had a letter to the editor on end of life costs in *The New York Times* (see below), was on a Public Access TV program broadcast in various communities in Westchester County, speaking about Compassion & Choices and end-of-life decision making, had a letter supporting medical marijuana published in the *Albany Times Union* and had an op-ed piece in the *Journal News* on the enactment of the *Family Health Care Decisions Act* and the continued importance of completing a health care proxy. Judy Schwarz was on *WBAI Ethics on the Air* speaking about Compassion & Choices and the work we do, and she had comments in a blog managed by the *American Journal of Nursing* on the use of palliative sedation, following a *New York Times* article on the subject.

### January 2, 2010 *The New York Times* To the Editor:

Most dying patients want to know their prognosis and what options are available. They want to devise, with their doctors' help, goals of care after learning about the risks and benefits. When end-of-life discussions occur, costs decrease because, armed with information, far more patients decide to forgo aggressive, costly treatments that often cause unnecessary suffering. Research has shown that twice as many patients who have had discussions with their doctors have "do not resuscitate" orders, are much less likely to have mechanical ventilators, and are far more likely to enroll in hospice programs for more than a week. More doctors and patients need to have these important end-of-life discussions.

**David C. Leven**  
Executive Director, C&C of New York

## message

from the Executive Director

### fill out that health-care proxy form now

In March, landmark health-care legislation impacting tens of thousands of New Yorkers was signed into law by Gov. David Paterson. Under the *Family Health Care Decisions Act* (a summary outline is in this newsletter) loved ones will now be able to make health-care decisions for patients who have lost the ability to do so, in certain situations and under rigid criteria, when those patients have not completed a health-care proxy or a living will. This law is significant as the vast majority of New Yorkers have not, often to their detriment, appointed a trusted person to be their health-care agent by completing a health-care proxy form.



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

The importance of this legislation, however, does not diminish the need to complete a health-care proxy. In fact, it is still critically important to do so for many reasons, if you want your health-care wishes to be respected. A fundamental reason is that the *Family Health Care Decisions Act* has many stringent limitations and criteria for surrogate decision-making, which do not limit the agent you would appoint when you complete a health care proxy. For example, it applies only to decisions in general hospitals, nursing homes and residential health-care facilities. Thus, a surrogate is not authorized to make health-care decisions for a patient at home whether in hospice or not.

Additionally, the decision-maker is chosen in order of priority from a hierarchy, with a spouse or domestic partner first, followed by an adult child. And, while a challenge can be made by one lower in the hierarchy, in many cases it is likely that a person will be authorized to make health-care decisions for patients who the patients would not

Continued on page 2

## Baxter, et al v. Montana

### Victory for patients, families and physicians in Montana!

Montana physicians, terminally-ill patients and Compassion & Choices hailed the Montana Supreme Court's ruling that terminally ill Montanans have the right to choose aid in dying under state law. The court ruled that public policy of Montana does not criminalize, and much in current public policy affirmatively supports, aid in dying. The court did not reach the question of whether the Montana constitution specifically protects aid in dying.

There is no appeal from this decision, as the Montana Supreme Court is the highest court available to decide State issues in Montana.

In a detailed review of Montana law on the "Rights of the Terminally Ill," the Court concluded that the existing legislation specifically defers to a patient's own decisions and affords patients the right to control their own bodies at the end of life. The decision to self-administer life-ending medication should receive the same treatment as a decision to discontinue life sustaining therapies such as mechanical ventilation.

The court said, in a ringing rejection of arguments by the state: "The State asserts that it has compelling interests in preserving life and protecting vulnerable groups from potential abuses. This broad assertion, however, is entirely inadequate to sustain the State's position in opposition to physician aid in dying. We are dealing here with persons who are mentally competent, who are incurably ill, and who expect death within a relatively short period of time. The State has failed to explain what interest the government has in forcing a competent, incurably ill person who is going through prolonged suffering and slow, excruciating physical deterioration to hang on to the last possible moment."

Compassion & Choices Legal Director Kathryn Tucker, co-counsel to the plaintiffs/respondents, said, "This case was about the right of mentally competent, terminally ill patients to request a prescription for medication from their doctors which they can ingest to bring about a peaceful death. The Montana Supreme Court has determined that this is a choice the public policy of Montana supports. Montanans trapped in an unbearable dying process deserve, and will now have, this end-of-life choice. This is the first state high court to find protection of this choice, and makes clear that in Montana, patients are able to make this choice and physicians can provide this care without risking sanction."



Kathryn Tucker, Compassion & Choices Director of Legal Affairs

***This case was about the right of mentally competent, terminally ill patients to request a prescription for medication from their doctors which they can ingest to bring about a peaceful death.***

# Family Health Care Decisions Act signed into law

The Family Health Care Decisions Act, (FHCD A), signed into law by Governor David Paterson on March 16, establishes the authority of a patient's family member to make health care decisions for a patient in cases where the patient lacks decisional capacity and did not leave prior instructions or appoint a health care agent. The family member's decision-making authority includes the authority to direct the withdrawal or withholding of life-sustaining treatment when standards set forth in the statute are satisfied.

Until this legislation was enacted, unless a health care agent had been appointed pursuant to a completed health care proxy form, there was generally no legal basis for a family member to make health or end-of-life decisions on behalf of a patient who lacks decision-making capacity. Instead, decisions to withdraw or withhold treatment could be made only where there was "clear and convincing evidence" of the patient's wish to refuse such treatment. Moreover, when a patient lacked capacity, family members lacked clear authority even to consent to beneficial, desired treatment. While health care providers routinely, and

out of necessity, accepted treatment consent from a family member or close friend for beneficial treatment, there was only thin legal support in New York for that practice.

## Summary of Key Provisions of the FHCD A

### 1. Applicability

Applies to decisions in general hospitals, nursing homes and residential health care facilities.

Does not apply to decisions for patients:

- who have a health care agent.
- who are mentally retarded and have a court-appointed guardian .

### 2. Determining Incapacity

Sets forth a hospital-based process to determine that a patient lacks decisional capacity. In general, the process requires an initial determination by the attending physician, and a concurring determination by a "health or social services practitioner," a broader category of professionals.

Provides that if the patient objects to the determination of incapacity, or to the choice of a surrogate, or to a surrogate's decisions, the patient's decisions prevails unless a court finds that the patient lacks capacity, or another legal basis exists for overriding the patient's decision.



Governor David Paterson signing the Family Health Care Decisions Act into law, March 16.

### 3. Decisions for Patients who Lack Capacity

Sets forth, in order of priority, the persons who may act as a surrogate decision-maker for the incapable patient, i.e.:

- a Mental Health Law Article 81 court-appointed guardian (if there is one);
- a spouse or domestic partner
- an adult son or daughter
- a parent
- a brother or sister
- a close friend (who could be another relative)

*Continued on page 3*

## health care proxy...Continued from page 1

have chosen had they been appointing a person make decisions for them. Moreover, the FHCD A requires the surrogate to decide about treatment based on the patient's wishes, including the patient's religious and moral beliefs, or, if the patient's wishes are not reasonably known and cannot with reasonable diligence be ascertained, based on the patient's best interests. If you have not conveyed your wishes to loved ones, decisions may well be made that are contrary to what you would have decided.

### Strict standards apply

Finally, the act only authorizes decisions to withhold or withdraw life-sustaining treatment if treatment would be an extraordinary burden to the patient and the patient is terminally ill or permanently unconscious, or if the patient has an irreversible or incurable condition and the treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under

the circumstances. Certain decisions require ethics committee review. These are very strict standards, difficult to meet and not applicable to health-care agents.

What all of us need to do, whether or not we have someone to appoint as our health-care agent, is to have conversations with loved ones about our goals of care, values, preferences and specific care and treatment that we would want or not want in various situations. If a trusted loved one does exist, ask that person to be your health-care agent (a person you think will make decisions you would make for yourself and will be a strong advocate for you). The health-care proxy form is a simple, two-page document that can be completed without the help of lawyers.

If you have these conversations and appoint a health-care agent, it is far more likely that your wishes will be honored. You will also make it so much easier for loved ones who will not have to guess what your

wishes are. Unfortunate conflicts can be avoided among family members who, while acting in good faith in your best interests, disagree about what your treatment preferences might have been because you never conveyed them.

### Lifting a burden

Placing such a burden on your loved ones is really unfair. If you complete a health-care proxy you may also spare your loved ones the torment and guilt of keeping you alive in futile circumstances or when choosing to terminate care that you have informed loved ones you would not want. The FHCD A was urgently needed to enable loved ones of patients without decision-making capacity to make health-care decisions for them. However, it is no substitute for having a person who knows your values, wishes and preferences and who has been appointed by you as your health-care agent. Do not delay. Get a health-care proxy form and complete it today.

Grants the surrogate authority to make all health care decisions for an adult patient that the patient could make for himself or herself, subject to certain standards and limitations.

States that health care providers do not need a surrogate's consent for a health care decision if the patient previously made the decision, either orally or in writing.

Requires the surrogate to decide about treatment based on the patient's wishes, including the patient's religious and moral beliefs, or, if the patient's wishes are not reasonably known and cannot with reasonable diligence be ascertained, based on the patient's best interests.

Authorizes decisions to withhold or withdraw life-sustaining treatment if treatment would be an extraordinary burden to the patient and the patient is terminally ill or permanently unconscious, or if the patient has an irreversible or incurable condition and the treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances. Certain such decisions require ethics committee review.

Authorizes the parent or guardian of a minor patient to decide about life-sustaining treatment, in accord with the same standards that apply to surrogate decisions for adults. In addition, if a minor has the capacity to decide about life-sustaining treatment, the minor's consent is required to withhold or to stop treatment.

#### 4. Resuscitation-related Provisions

Eliminates much of NY's DNR (Do Not Resuscitate) Law as applied to hospitals (because DNR decisions would be governed by the FHCDA).

Creates a new *Public Health Law, Article 29-CCC*, to retain (with some modifications) existing provisions on nonhospital DNR orders.

#### 5. Effective Date

Hospitals and nursing homes were required to implement the FHCDA by June 1, 2010

\*This is part of a document prepared by Robert Swidler, General Counsel and Vice President, Legal Affairs, Northeast Health, Troy, NY, with minor revisions made, following the bill's enactment, by David C. Leven, Executive Director, Compassion & Choices of New York.



## C&CNY holds meetings at All Souls Unitarian Church

Compassion & Choices of New York is now holding three scheduled meetings a year at the All Souls Unitarian Church in Manhattan to discuss relevant death and dying issues. At the first meeting in January David Leven, C&CNY Executive Director and Judith Schwarz, C&CNY Clinical Coordinator, both spoke. David gave an update on litigation and legislation activities across the country and in New York to improve care and expand choice at the end-of-life. Judy spoke about the counseling services that we provide. In May Judy and David spoke about advance care planning to ensure that patient wishes are respected and specifically about health care proxies, Medical Orders for Life Sustaining Treatment (MOLST), Living Wills and the new Family Health Care Decisions Act.

## "Stories From The Bedside: End-of-Life Conversations, Choices & Planning" a huge success

The program "Stories From The Bedside: End-of-Life Conversations, Choices & Planning" at and co-sponsored by The New York Society for Ethical Culture was a huge success with four excellent speakers and an audience of over 160. The program featured the Rev. Jennifer Brower, a daughter of a patient and minister at Unitarian Universalist Congregation at Shelter Rock in Manhasset, who spoke about her mother's dying process and death; Dr. Joanna Sheinfeld, Mt. Sinai Medical Center, and a Visiting Doctor, who spoke about several dying patients and lessons learned; Judith Schwarz, PhD, RN, C&CNY Clinical Coordinator, who spoke about different patient scenarios at the end-of-life and our counseling of those patients; and Jane Brody, the prominent New York Times health columnist, who writes on death and dying issues. She urged the audience to complete advance directives and recommended "Jane Brody's Guide to the Great Beyond" which gives useful information on what people planning for the end of their lives should consider doing.



Jane Brody



Rev. Jennifer Brower

## Schwarz is keynoter at nurse's conference; lectures lawyers and nurses

On April 15th Judith Schwarz provided the keynote address for the NJ End of Life Nursing Education Consortium (ELNEC) sponsored by Rutgers University continuing education in nursing, with some 100 nurses in attendance. She also gave a workshop immediately after the key note. Her keynote address was a general discussion about palliative care and responding to a patient's desire for death. The workshop dealt almost exclusively with voluntarily stopping eating and drinking (VSED), as an option that nurses ought to discuss with patients who wished EOL information.

Judy gave an hour long presentation to the Trust and Estates Department of the law firm, Skadden, Arps, Slate, Meagher, & Flom about the *clinical reality* of advance medical planning and documentation of EOL wishes.

Judy delivered a talk to RN, BSN students in the CUNY Hunter nursing program on end of life issues.

## Leven educates professionals and students

During the spring David Leven gave a number of talks to health care professionals. He gave a lecture to graduate nursing students at College of New Rochelle Nursing School on End-of-Life Issues and Choices, gave a talk to Westchester Consortium for Palliative Care on the new *Family Health Care Decisions Act*, debated Wesley Smith, JD, on physician aid in dying at Columbia Law School, lectured lawyers at The New York City Bar Association on the *Family Health Care Decisions Act*, was the lead panelist speaking on aid in dying at Fairleigh Dickinson University following the play "Whose Life is it Anyway" and lectured lawyers at Pace Law School on end-of-life issues.