

# connections

## voluntarily stopping eating & drinking – a peaceful way to die

*Judith Schwarz, RN, PhD, Patient Support Coordinator*

The patient support team of Compassion & Choices of New York works with all those who contact us seeking our counsel and support. Most often, patients or their families contact us following a sudden change in their health – when told that they have entered the “terminal stage” of their disease, or when they hear bad news, e.g., that their disease is no longer in remission and they will not benefit from further life-prolonging measures. As many of our members know, we provide information and support to those terminally ill and decisionally capable persons who contact us wanting to stay in charge of options and choices as the end of life nears.

Some who contact us are not yet in the terminal stage of disease, yet their suffering may be intolerable, and they too seek support and information about how they might hasten their dying if no other measures to relieve suffering are found. Increasingly, competent, chronically ill persons who are often frail and elderly turn to their families or close friends for aid in dying; those concerned family members or friends then contact C&C of NY. We arrange a meeting with the patient and their family members to discuss the benefits and burdens of various end-of-life options that can facilitate a gentle, hastened death – such as stopping all life-prolonging interventions (like implanted cardiac defibrillators) and/or medications – and we also discuss the option of stopping eating and drinking. We know from our experience in working with others who have chosen this option that ‘voluntarily stopping eating and drinking’ (VSED) can provide a gentle and peaceful death, providing the patient has hospice and family support, and is determined that this is an appropriate option of ‘last resort’ to hasten dying. A VSED death is very much like the natural dying process that is seen as dying patients routinely lose interest in food or fluids as death nears.

Although many patients and family members fear that VSED would result in a painful death – involving prolonged suffering

thought to be caused by death by starvation – such fears are quite unfounded. Death is caused by dehydration rather than lack of food, and most patients slip into a very sleepy state several days after beginning to fast; death occurs within 1-3 weeks, depending upon



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*— Judith Schwarz, C&C of NY Patient Support Coordinator*

the patient’s underlying disease or physical condition. The most significant advantage of VSED is that this option is a legally/ethically supported choice that any competent person can make to hasten dying when their suffering cannot otherwise be relieved, and is a decision that can be privately made with loved ones and initiated without requiring medical permission. C&C volunteers work closely with the patient and family to ensure that this process unfolds in a thoughtful and well-planned manner, and that patients are well supported by hospice clinicians and other care givers, so that a peaceful gentle death occurs in the setting chosen by the patient.



## message

from the Executive Director  
the language of death matters

Terminology is important and we who support choice in dying should be using language which is likely to gain supporters. The term "assisted suicide" is one with negative connotations, used by our opponents and unfortunately too often by some supporters of choice in dying, including the media, but it is clearly not an accurate term. It is time for all of us to stop using it even if we as individuals do not think there is a problem with the term.



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

As Dr. James Lieberman (a former Compassion Board member) commented in a letter to the editor of *Psychiatry News* (August 4, 2006) comparing suicide patients with those using the provisions of the *Oregon Death with Dignity Act (DWDA)*:

- The suicidal patient has no terminal illness but wants to die; the DWDA [patient has a terminal illness and wants to live.
- Typical suicides bring shock and tragedy to families and friends; DWDA deaths are peaceful and supported by loved ones.
- Typical suicides are secretive and often impulsive and violent. Death in DWDA is planned; it changes only timing in a minor way, but adds control in a major and socially approved way.
- Suicide is an expression of despair and futility; DWDA is a form of affirmation and empowerment.

In *Gonzales v. Oregon*, an American Psychological Association working group wrote, "It is important to remember that the reasoning on which a terminally ill person (whose judgments are not impaired by mental disorders) bases a decision to end his or her life is fundamentally different from the reasoning a clinically depressed person uses to justify suicide."

In November the American Public Health Association issued a position statement which reads, in part,

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## legislation passed on health care proxies

Crafted by Compassion & Choices of New York, legislation was passed, which should increase the number of people who complete health care proxies. The bill requires the Department of Health to conduct education and outreach programs for consumers, patients, and health care providers relating to the need and importance to have an advance directive, particularly a health care proxy. It requires the Department of Health specifically to educate health care providers about the need and importance for them to play a leadership role in discussing end-of-life care preferences and values with patients and to provide patients with health care proxy forms.

Another bill initiated by Compassion & Choices requires the Department of Motor Vehicles to distribute, in license and vehicle registration mailings to New York residents, a health care proxy form and instructions as prepared by the Department of Health in collaboration with the Commissioner. The Department of Motor Vehicles would conduct such mailings throughout the entire calendar year once every four years. We are hopeful that this bill will be passed next year.

## palliative care education & training act enacted

The *Palliative Care Education and Training Act* was enacted this year. Initiated by Compassion & Choices to improve palliative care and pain management, it is the first bill of its kind in the nation. The legislation addresses, in a number of meaningful ways, the urgent public health care crisis of the undertreatment of pain. In summary, the legislation will do the following:

- Establish a statewide advisory council on palliative care and pain management;
- Create undergraduate and graduate palliative care training programs;
- Establish Department of Health-designated Centers for Palliative Care Excellence; and
- Authorize the Department of Health to certify one or more palliative care resource centers to assist physicians in the treatment of patients in pain.
- Up to \$4.5 million is authorized annually for training programs.

"Many health care professionals are unaware of the new resources available for their patients to relieve pain," said Assembly Health Committee Chair Richard N. Gottfried (D-Manhattan), sponsor of the Assembly bill. "This legislation will help train physicians and other professionals to relieve the suffering of thousands of New Yorkers." I am grateful that Compassion & Choices of New York took the initiative to work with us on this important legislation."

Senator Kemp Hannon, (R-Long Island) Chair of the Senate Health Committee and



Assembly Health Committee Chair, Richard Gottfried (above); Senate Health Committee Chair, Kemp Hannon.

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# Oregon's ninth year numbers document improved end-of-life care

The Oregon Department of Human Services (ODHS) ninth annual report on the *Death with Dignity Act* confirms that Oregonians benefit from improved end-of-life care under the statute.

A tiny number of the 31,000 people who died in Oregon in 2006 – only 46-patients hastened their deaths by self-administering medications. All but one of the terminally ill residents who chose the option had health coverage and all had access to hospice services. Oregon has the lowest rates of in-hospital deaths and the highest rates of home deaths in the nation.

In 2006, three-quarters of the patients who took the medications were enrolled in hospice. Executive Director of the Oregon Hospice Association (OHA) Ann Jackson summed up the results saying, "In its first nine years, the *Oregon Death with Dignity Act* has been responsibly implemented with none of the predicted dire consequences." The OHA takes a neutral position on the law but supports the right to receive optimal hospice care, regardless of whether a patient is considering aid in dying.

The report is also notable this year for its use of value-neutral language to describe a patient's choice for aid in dying. ODHS no longer uses the emotionally charged term "assisted suicide," instead referring to "persons who use the *Oregon Death with*



Ann Jackson, Executive Director, Oregon Hospice Association.

*Dignity Act.*" The new language reflects the intent of the law which states, "Actions taken in accordance with (*Oregon's Death with Dignity Act*) shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law."

Compassion & Choices President Barbara Coombs Lee told reporters, "Those who died using the law in the last nine years were able to fulfill their wishes for safe, peaceful deaths. The time has come for other states to follow Oregon and stop obstructing the dying wish of many mentally competent, terminally ill patients."

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The term "suicide" or "assisted suicide" is inappropriate when discussing the choice of a mentally competent terminally ill patient to seek medications that he or she could consume to bring about a peaceful and dignified death.

Accordingly, recognizing the importance to public health of using accurate language, APHA urges that health educators, policy makers, journalists, healthcare providers recognize:

- that the choice of a mentally competent terminally ill patient to choose to self administer medications to bring about a peaceful death is not "suicide", nor is the prescribing of such medications by a physician "assisted suicide.";
- that accurate, value-neutral terms such as "aid in dying" or "patient directed

dying" be used to describe this choice.

And in February the American Academy of Hospice and Palliative Medicine issued an excellent position statement entitled "Physician-Assisted Death" on how to work with people who, at the end of life, wish to hasten their deaths. While stating that the AAHPM "takes a position of "studied neutrality" on the subject of whether PAD should be legally regulated or prohibited, regard terminology, it stated the following:

"Excellent medical care, including state-of-the-art palliative care, can control most

symptoms and augment patients' psychosocial and spiritual resources to relieve most suffering near the end of life. On occasion, however, severe suffering persists; in such a circumstance a patient may ask his physician for assistance in ending his life by providing Physician-assisted Death (PAD). PAD is defined as a physician providing, at the patient's request, a lethal medication that the patient can take by his own hand to end otherwise intolerable suffering. The term PAD is utilized in this document with the belief that it captures the essence of the process in a more accurately descriptive fashion than the more emotionally charged designation Physician-assisted Suicide."

The Oregon Health Services Department, too, is no longer using the term assisted suicide and now refers to the process as "people who use *Oregon's Death with Dignity Act.*"

Consider the statement of Jack Newbold a terminally ill man in Oregon who had obtained a lethal dose of medicine under the *Oregon Death with Dignity Act*. He said at a news conference that he resented media reports that he is about to "kill" himself. "I've got just a few days left to live, and I don't want to put my wife and family through a prolonged death. I'm not committing suicide, and I don't want to die. But I am dying, and I don't want someone dictating to me that I've got to lie down in some hospital bed and die in pain.

"I was upset by media reports that I intend to 'kill' myself. I'm not killing myself; cancer is taking care of that. I may take the option of shortening the agony of my final hours."

Finally, polls show less support for aid in dying when the word suicide is used. In one poll, when asked if doctors should be allowed to help end the life of a patient who is suffering from an incurable disease and wants to die, 75% of Americans say "yes." But when asked if doctors should be allowed to help a patient commit suicide under the same circumstances, only 58% of Americans say "yes."

It is time for us to use language that will best serve the purposes of our movement. What language is used does influence our thinking and how we feel about things, especially when it comes to emotional and controversial issues such as aid in dying.

"Aid in dying" or "physician aid in dying" are terms that will, in general, be more accepted by the public and by politicians. Let's use them.



Dr. Russell K. Portenoy, President-elect of the American Academy of Hospice and Palliative Medicine.

## compassion in the classroom

Executive Director David Leven was the guest lecturer at a number of college classes this spring including at Fordham University and Touro College, and College of New Rochelle Nursing School. David also lectured at Pace Law School. Patient Support Coordinator Judith Schwarz gave two lectures at College of New Rochelle Nursing School.

## Leven has letters to the editor published on Kevorkian release

Both the *New York Times* and *The Journal News* (Westchester-Rockland-Putnam) published letters to the editor written by David Leven. *The Journal News* letter is reprinted below:

*The Journal News, June 10, 2007*

*Replicate Oregon's law on assisted dying*

*After serving eight years in prison for illegally helping terminally or chronically ill people to die, Dr. Jack Kevorkian has been paroled. Most people are unaware that what Dr. Kevorkian did is not uncommon. In fact, aid in dying is happening: underground, unregulated and illegally. The practice should be legalized with strict regulations and safeguards, as in Oregon.*

*There, physicians may prescribe lethal medicines for their dying patients (which the patients must self-administer) after two physicians have determined that the patient is terminally ill following three requests, one in writing (with two witnesses) and no indication of mental illness.*

*The law has been a model for the nation, with no abuses. None of the problems anticipated by opponents have emerged. Only 292 people, in nine years, have taken the lethal medicines, about one in 800 dying Oregonians. While few have used the law, those who are dying are reassured that if suffering becomes unbearable, they have a last-resort remedy. Almost all who have hastened their deaths have had health insurance and family support. Close to 90 percent were enrolled in hospice, about three times the national average. The law has been used primarily by college-educated, middle-class people who are dying from cancer, heart disease, Amyotrophic Lateral Sclerosis and AIDS.*

*Oregon's law should be replicated nationwide. Doing so would allow dying people to have a peaceful and dignified death, not a continued agonizing dying process, or a life that is ended violently or by illegal means.*

David C. Leven

Pelham

*The writer is executive director of Compassion & Choices of New York.*

**Your support in 2007 is greatly needed,  
please use the enclosed envelope for your contribution.**

**For information of considering Compassion in your will and other planned gifts,  
please contact David Leven at [ny@compassionandchoices.org](mailto:ny@compassionandchoices.org).**

## CA assembly fails to pass compassionate choices act

The *Compassionate Choices Act*, which if passed, would have made California the second state in the nation to have a physician aid in dying law, did not have enough votes to pass the Assembly and so it did not come up for a floor vote. While a large majority of Democrats had planned to vote for the bill, and the Speaker of the Assembly was a lead sponsor of the bill, all 32 Republicans, it was reported, would have voted against it.

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lead Senate sponsor said, "Passage of this legislation is an important step to ensure that in the future patients will get effective palliative care and pain treatment. I am excited that those with expertise in the field across the state and across disciplines will be working with and advising the Commissioner of Health."

David Leven, Executive Director of Compassion & Choices of New York, said, "The medical community came together on this bill, as there was a general awareness that other efforts to improve pain and palliative care in New York have not proceeded rapidly enough. This bill will serve as a model for the nation."

***"This is critically important legislation. I have no doubt that the proper implementation of this bill will substantially increase the number of physicians who will be able to effectively treat the pain of their patients and provide excellent palliative care to their seriously ill patients."***

— Dr. Patricia A. Bomba, Vice President and Medical Director, Geriatrics, Lifetime Healthcare Companies, MedAmerica Insurance Company