

# compassion & choices of the National Capital Area



Support Educate Advocate

*Serving Maryland, Virginia and the District of Columbia*

June 2008



## A Simpler Version of Medical Advance Directive

Last April 16 was National Health Decisions Day, similar to one we participated in last year. At tables set up in shopping malls, senior centers, hospital lobbies and libraries, we try to convince more people to complete an Advance Directive (AD). That is not easy, because people glance at these documents, find them scary, and do nothing about them.

If we hope to have more people complete an AD, we need a document simpler in its language and much simpler in the medical situations considered.

Jim Lieberman and Don Wentzel represent C&C and Choices on the Montgomery County Coalition for End-of-Life Care. This group has constructed a short, plain version of the AD, only six pages long, titled CHOICE OF HEALTH CARE AGENT.

It deals solely with the legal appointment of a Health Care Agent and a back-up Health Care Agent. It is designed to meet legal requirements of at least three jurisdictions--Maryland, Washington DC and Virginia--since people living in one of these locations often use a health facility in a neighboring area.

There is no explicit Living Will and no mention of specific medical problems. Instead, the person is encouraged to discuss medical wishes with family and with the Health Care Agent. Then the person is asked to write down his or her thoughts and preferences on a range of questions, for instance "How important is it for you to avoid pain and suffering?" This is intended as advice to the Health Care Agent.

The Agent, as personal advocate, is central, because a patient, arriving at a hospital unable to communicate, cannot expect a Living Will to be followed automatically. Enforcing one's wishes may require active intervention by a designated advocate. Our short, relatively simple AD gives the Health Care Agent this essential role. (continued on Page 2)

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### C&C website:

[www.compassionandchoices.org](http://www.compassionandchoices.org)

Go to tab for "Get Involved" and select "In The Community" from the drop-down box. You can then browse the dates and location of upcoming meetings.

**To speak with a Client Support counselor or for membership information, please call the national office at:**  
**1-800-247-7421**

(continued from front page) Virginians may prefer the short, plain version because it allows immediate appointment of the Health Agent, while the standard Virginia version empowers the Health Agent only when necessary in the judgment of doctors.

This is not a form for everyone. If the patient wants to specify precisely what treatments are wanted or not wanted, then the standard form is better. If the patient is worried about legalities like HIPPA regulations, the standard form may be better, especially the state-model form of Maryland. But we think most people are better off with a completed, short and simple AD than with a standard one left blank in a desk drawer.

We are getting additional feedback on this form. We expect to translate it into five other languages. Meanwhile, if you or someone you know should initiate or renew an AD, please request the new form from us by email [choicesnca@earthlink.net](mailto:choicesnca@earthlink.net) or phone: 202-347-2056.

A standard AD form can be obtained at the C&C website. Substitute DC or VA for MD to obtain forms for the different jurisdictions. Go to [www.compassionandchoices.org/ad/ad\\_pdf/MD.pdf](http://www.compassionandchoices.org/ad/ad_pdf/MD.pdf). The detailed, model AD for Maryland can be obtained at [www.oag.state.md.us/Healthpol/AdvanceDirectives.htm](http://www.oag.state.md.us/Healthpol/AdvanceDirectives.htm) and can be adapted for DC and MD by changing the qualifications of the witnesses.

»»»»Don Wentzel

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### **Concerns about Treatment and Catholic Hospitals**

Earlier this year, at our Washington DC meeting, speaker Matthew Nelson, board member of Compassion and Choices, read from the Ethical and Religious Directives (ERDs) for Catholic Health Care Services. Several of the ERDs raise concerns for us about end-of-life care. One states that advance directives will be followed to the extent that they conform with ERDs. Another: that deliberately hastening death, whether with medication as in Oregon or by refusing food and water, would be prohibited. Another: that if pain cannot be adequately controlled, patients "should be helped to appreciate the Christian understanding of redemptive suffering."

This information stirred considerable discussion, as the Pope's visit was upcoming. Our letter about the implications of the ERDs for practice at Georgetown University Hospital, a leading Catholic institution, led to a meeting of three of us (Don Wentzel, Carolyn Drake Compton, and Jim Lieberman) on April 7 at the Center for Clinical Bioethics at GU with Carol Taylor, RN, PhD, Director, and several others. The meeting was cordial, frank, and quite reassuring, although one of their group warned that too many doctors are inclined to let patients die. There are differences in levels of adherence to the Directives; the impression given was that humane care with flexible interpretation prevailed over rigid adherence to dogma. An instance was given where a doctor would not refer a patient elsewhere for a procedure that he considered immoral under the directives, but the implication was that such strictness was not typical.

We were assured on several points. There is latitude for doctors practicing in Catholic hospitals. Examples from reproductive health illustrate: abortion is banned, and the pharmacy may not carry some contraceptives, but physicians can prescribe contraception and refer elsewhere for abortion (though some devout MDs may choose not to).

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(continued from page 2) With regard to end-of-life care, palliative sedation is practiced at the discretion of the physician, even if death is hastened incidentally--not deliberately. Patients can refuse treatment, including feeding tubes and ventilator. One of our members submitted his advance directive to another Catholic hospital, Holy Cross in Silver Spring, asking whether it would be honored, and received written assurance on all points except one: refusing food and water might not be acceptable, but this is usually an issue for hospice, not hospital. Carol Taylor said that the response he received would be the same from Georgetown.

The influence of the Catholic hierarchy varies with the institution and its doctors. Catholic hospitals, like others, need to be economically viable as well as effective and humane. They do not want to alienate the public--the current and future source of patients and doctors among whom devout, observant Catholics are a small minority. *The Washington Post* published a survey April 13 showing that U.S. Catholics, compared with all adults, are more liberal on issues including abortion, the death penalty, and legalizing gay civil unions.

Several points should be emphasized for our members. First, know what your primary care physician will and will not do. Choose one who is sympathetic to your wishes and philosophy. Second, have an advance directive in case you must be hospitalized when unable to speak for yourself. More important than the specific requests you make in the AD is the appointment of a health agent, or power of attorney for health care. If you are not competent to speak for yourself you need an advocate, not just a paper document. Remember to appoint a backup person in case your first choice is not available. Inform your family members and the agents about your wishes, in writing. Third, remember that in an emergency, ADs might not be followed. If you find yourself in a hospital receiving treatment you do not want, you or your agent can request cessation of treatment and/or transfer. On rare occasions the advice of an informed attorney or intervention of a hospital ethics committee has helped. C&C wants to hear of cases where a patient's wishes are not followed, and is ready to help when asked.

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### **Notes from May 22, Chapter Meeting**

On Thursday May 22 at 11 AM we held a meeting of the Board of Compassion & Choices National Capital Area in McLean, VA. Interested members were invited (mainly from nearby Virginia, via postcard. To our pleasant surprise, 30 attendees, including Board members, participated. The topics included a brief business meeting followed by discussion of several topics of general interest:

Catholic hospital policy, hospice, and hospital mergers, Latest information on Advance Directives Client Support in the area: report from a counselor, Legislative activity here and nationally: guest presenter Nancy Buermeyer from Raben Associates.

Carolyn Drake Compton was elected to the board, and Ron Liesemer was elected Secretary. Treasurer Knick Knickerbocker's financial report was presented and unanimously accepted.

Because of the good turnout for a morning meeting on issues but without a prominent speaker, we will consider this a viable option in the future to engage more members face-to-face in varied locations around our large NCA area.

Please check the Compassion and Choices website for information about national and local events. There is a section on the site for community events, which we update whenever there is something planned in our area. [www.compassionandchoices.org](http://www.compassionandchoices.org) »»»»Don Wentzel, President, C&C NCA

## The Client Support Program

The National Capital Area Chapter Client Support Program will be three years old this June. We started with ten trained volunteers under the supervision of Dr. Judy Schwarz in New York and continue to conference monthly and as needed with her. Our Team has added some volunteers, and lost some. New volunteers are always needed and welcome.

We work mostly with the terminally ill and their families and close friends. Despite common assumptions about Compassion and Choices, we do not focus solely on hastening death. People seeking our help have many end-of-life concerns. We help with Advance Directives, concerns about pain control, hospice, nursing home care and advocacy, planning for the time near the end of life, and helping families deal with terminal illness by talking more openly. We offer support to those who are suffering but not yet terminal. We discuss the right to refuse medical treatment, food and fluids. We talk about palliative sedation. Of course we also offer information to the terminally ill, while they can still make their own medical decisions, about ways and means to hasten death. We will be there with any client hastening death if they wish. However, we cannot provide or administer the means for hastening death. We do not break the law.

Terminally ill patients are advised to enroll in hospice. Few are aware that 80 percent of hospice care is provided in the home, not in an institution. While Medicare funding of hospice is usually understood to apply to the last six months of life, there is flexibility, since prognoses can change, and predictions are estimates. Hospices seek a natural death for their patients. Many, but not all, will accept clients who wish to stop food and fluids to hasten death. Most hospices will provide total palliative care as well.

To obtain C&C support services, clients first call the national office (800-247-7421) to discuss their situation with a staff counselor. For those in the National Capital Area, Judy Schwarz is notified and calls a local volunteer to visit and help each client. Our local contact number is 202-347-2056.

We want our service to be better known. PLEASE LET YOUR FRIENDS KNOW ABOUT COMPASSION AND CHOICES. To me, C&C is about CHOICES, each person's right to their own choice, not a decision by a group of older uninformed men in Congress or members of a religious body enforcing their own personal beliefs. It is my right and yours to make our own choices!

»»»»Mickey Allardice, member of the Team



Too many suffer needlessly.  
Too many endure unrelenting pain.  
Too many turn to violent means at the end of life.

compassion & choices  
End-of-Life Consultation

"I felt alone until I called Compassion & Choices. They let me know I had choices and support. What a comfort that was."  
- Compassion & Choices client Tom McDonald

If you would like Client Support referral cards to give to friends or family, please call 1-800-247-7421. These 3½by 5½ cards inform patients they have a choice, and provides both national toll-free phone number and website address.

## National Notes

Members who read the Compassion and Choices Magazine, Spring 2008, may recall a discussion of the End-of-Life Consultation program. That is, in fact, the Client Support program, renamed for better public recognition.

After the California state legislature failed to pass a Physician Aid-in-Dying law, C&C decided to stand up and say we are still doing this work: we are helping people within California. There were four press conferences led by clergy who are supportive of our cause.

In addition, Mark Ferguson, a social worker with the End-of-Life Consultation program, wrote an article in the newsletter of the California chapter of the National Association of Social Workers, letting the 15,000 members know that their clients have choices. A long article appeared in the *San Francisco Chronicle* (June 8) including this quote: "It's our position that this kind of consultation isn't illegal at all," said Barbara Coombs Lee, president of Compassion & Choices, which last year worked with 2,500 people around the country. "Keeping it secret and shameful is part of keeping people powerless. It's extremely empowering to have the knowledge."

In the meantime, The California Assembly voted and passed the Terminal Patients' Right to Know End-of-Life Decisions Act (AB 2747, Berg-Levine). The Act provides terminally ill patients with a full disclosure of, and counseling about, all available legal and ethical end-of-life care options currently available to Californians. When requested, information about hospice care, voluntary stopping eating and drinking (VSED), refusal or withdrawal of life-prolonging treatments, palliative care and palliative sedation would be discussed with the patient. The Act also requires that health care providers who do not wish to comply with a particular patient's choice must refer or transfer the patient to another provider.

In the State of Washington efforts continue to collect the 225,000 valid signatures needed to place an Oregon-style Death with Dignity initiative on the November ballot. The initial campaign, being conducted by Yes of I-1000 (for the number of the proposed initiative) is spearheaded by former Washington State Governor Booth Gardner. Gardner is suffering from Parkinson's Disease, a condition that would not make him eligible to use the law, but he sees passing the law as a legacy and has called it his "final campaign."

As of June 12, 2008, a total of 133,000 signatures had been collected. Yes on I-1000 has until July 3rd to collect the remaining signatures. Those interested in contributing financially to support the I-1000 effort can do so online at [www.itsmydecision.org](http://www.itsmydecision.org). Look for the "contribute" bar on the left hand side.

Yes on I-1000 is not affiliated with C&C, but our organizations are working together on the effort, with Yes on I-1000 collecting the signatures and C&C conducting public education programs explaining the experience of the Oregon's Death with Dignity Act, which the Washington initiative is modeled after.