

compassion & choices of the National Capital Area



Support Educate Advocate

News & Views

November 2007

Serving Maryland, Virginia and the District of Columbia



Editorial: Hope

Imagine a patient declared to be in a vegetative state for months. Quite probably there are people claiming that there is no real hope for improvement, that one should let the poor patient go. The patient's Advance Directive may say so. I have subscribed to this opinion. But certainly there are others who feel "there is always hope". I want to report on one such case.

For two weeks I lived with a family where the father had a massive brain hemorrhage five years ago. Days later he was delivered home by the hospital and declared to be in a vegetative state. The family maintained hope for life and, after some search, found help to begin restorative efforts. After some months, he was weaned off tubes. They kept working with him. By now he has developed enough facial expression so that others can recognize a laugh; he can slowly move one hand or a finger; he has some vision; he can help spell words; and most importantly, all these signs show that he understands fully what is said to him. Many patients have said: "I want to live to see my children grow up". This man is seeing his children grow up! Of course, he is very dependent on family (and others') extensive care, and some patients might not want to be in this situation, either for lack of control or because of the imposition on the family. But this family does not treat the care as an imposition, it is part of what life deals. His wife cites the benefit of having met all these wonderful caring volunteers. Here is a case where hope for life and persistence were the proper path to take. In the future, I shall treat the expression "there is always hope" with more respect.

Don Wentzel, President
Compassion & Choices of the National Capital Area

Two Patients Challenge Montana State Constitution

Two terminally ill Montanans recently filed suit against the state asserting the right to die on their own terms. They were joined by four physicians and Compassion & Choices. For more information visit: www.compassionandchoices.org

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C&C website:

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

News from Our Community Groups

Our new Community Group at **Riderwood** in Silver Spring is flourishing under the direction of Carolyn Drake Compton. There have been two meetings with attendance of 105 and 45 people respectively: On June 5, Dr. James Lieberman spoke on "*A Psychiatrist Looks at the End of Life*" and on September 18, Jack Schwartz, Esq., Maryland Assistant Attorney General, spoke on "*Making Sense of Advance Directives and Living Wills*".

Two additional meetings took place in October, one featured Barbara Coombs Lee, president of C&C which included an update on legislative activities. The other featured Judith Schwarz, R.N., Ph.D. clinical coordinator for C&C on "*Working to Improve Care and Expand Choice at the End of Life*". All the meetings included discussion with the audience. For each session a DVD is available for \$5.00.

The **Baltimore Community Group** met with Jay A. Dackman, Esq. on September 29. His presentation on "*Marketing the Mission*" concerned the need to attract members one generation younger than those usually attending C&C meetings, especially if we hope to support any legislative efforts that must show broad popular support. He hopes to reach families who had a recent death and therefore are sensitive to end-of-life issues. Several people volunteered to help with a trial project in the Baltimore area. It was agreed that the "old" members (ahem...) attending this meeting would try to bring their "kids" to the next meeting (see below), again with Jay Dackman.

Next Baltimore Community Group Meeting

Saturday December 1, 2007
10: 30A.M. to Noon

Jay A. Dackman, Esq.

"Getting the next generation to work with the right-to-die movement"

Location: Johns Hopkins Interfaith Center
3509 North Charles Street, Baltimore
Questions/Information: 410-235-7760

The **Mount Vernon Group** met on Saturday October 27 to hear Lawrence D. (Larry) Egbert, M.D. discuss "*Being prepared for the end-of-life decisions*". Dr. Egbert is a member of the board of the National Capital Area chapter of Compassion and Choices, and Medical Director of Final Exit Network. Using personal experiences he reviewed the choices made in the development of the aid-in-dying movement and the many choices an individual must make to seek to insure a safe, legal and dignified death. The Community Group formed a council to plan and carry out future meetings.

About Community Groups

Community Groups establish their own mailing lists. If you wish to attend meetings and be added to the mailing list of one of these, please provide your name and e-mail (preferred) or US mail address or phone at:

410-235-7760	Baltimore Group
301-572-8019	Riderwood Group
703-780-6477	Mount Vernon Group

Readers interested in helping to start a new Community Group should contact Don Wentzel by phone (301) 816-2308 or via e-mail at: d.wentzel@worldnet.att.net.

We especially need a community group in southern Virginia.

Roy Torcaso 1910-2007

Family and friends of one of the founders of the Hemlock Society in the National Capital Area, met at Rockville Unitarian Universalist Church on October 27 to remember and honor him. A fighter for individual rights, he is known and admired for bringing a case that reached the Supreme Court in 1961 and gave him a unanimous victory against the state of Maryland, which had barred him from certification as a notary public because he refused to sign an oath professing belief in God. The 9-0 decision in *Torcaso v. Watkins* stands as a memorial to him and an example to all who embrace freedom of religion and a right to privacy.

Stopping Eating and Drinking: An End-of-Life Option

Judith Schwarz, RN, PhD
Clinical Coordinator, Compassion & Choices Eastern Seaboard

Compassion & Choices provides information and support to terminally ill, decisionally capable persons who contact us to learn how they can stay in charge of their own dying, as the end of life nears. C&C has a group of trained volunteers who work with clients in the National Capital Area regarding end-of-life choices. Most often, patients or concerned family members contact C&C (800-247-7421) to speak to a counselor following a major change in health, usually after hearing that they have entered the “terminal stage” of their disease or that their disease is no longer in remission and life-prolonging measures are no longer warranted.

Some clients who contact us are not yet in the terminal stage of disease, although they may be suffering from multiple chronic ailments that greatly diminish their quality of life. They want to know whether we can help them control the circumstances of their dying, in the event that their suffering continues, and no other measures to relieve their suffering can be found. Increasingly, these chronically ill persons, who are often frail and elderly but still decisionally capable, turn to their family members or other loved ones and plead for help. They want to know how they can escape their bodies and their diseases--but they don't want their loved ones to get into trouble! When we finally hear from their families, these very determined folks have often been making that same request for months if not years. They want help in dying, to end prolonged suffering, to leave in peace, with dignity.

When possible, we talk in person with these patients and their families. Such meetings generally occur after the family member, or the client, has completed the intake interview over the phone with one of the counselors in Oregon. When clients are not currently terminally ill, we need to know that they have decisional capacity, that the decision is theirs alone, voluntary and informed, that they understand the consequences of their choice, are aware of alternatives, and that they can make and communicate a decision that endures over time. If there are questions about capacity, we might recommend consultation with a psychologist or psychiatrist--especially when a client has been diagnosed with “early” Alzheimer's disease or other dementia.

Where capacity is assured, suffering is non-relenting, and the client wants to know how death can be legally hastened, we discuss the benefits and burdens of end-of-life options that can facilitate dying. That includes stopping life-prolonging interventions (like implanted cardiac defibrillators) and/or medications. We also discuss voluntarily stopping eating and drinking (VSED).

We know from experience that VSED can provide a gentle and peaceful death if the client has family support, good care, and a determined will to hasten dying. A VSED death is very much like the natural dying process of patients with systemic disease. Usually there is loss of interest in food and fluids as death nears. Fasting patients in this state rarely suffer from hunger or thirst. Because they will become weak and soon will be confined to bed, caregivers then will be needed around the clock.

Clients and family members often fear that a decision to stop all oral intake will result in a painful death. Initially they associate VSED with painful death by starvation. However, 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 and become unconscious as their body goes into organ failure. Death occurs after 1–3 weeks of fasting, depending on the underlying disease and physical condition. This process is usually peaceful and uneventful, but we recommend that clients and families have home hospice care (if eligible) or an available and attentive physician. Occasionally, as death nears, some patients may experience delirium. This can be upsetting for the family, although the patient is usually unconscious. The hospice nurse or physician can provide sedation to (continued on back)..

According to a report in the October issue of the *Journal of Medical Ethics* (2007: 33:591-597) "people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional, and other privileges." Physician and philosopher Margaret P. Battin (Univ. of Utah) and colleagues investigated whether vulnerable groups--elderly, uninsured, minorities, poor, less-educated--are over-represented among patients who receive aid-in-dying where it is legal. There was no evidence of a heightened risk for these populations nor for those with non-terminal disabilities, which includes newborn infants with severe deficits and patients with psychiatric illness, including depression and dementia.

Oregon's Aid-in-Dying not a Slippery Slope

compassion & choices

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Newsletter of the National Capital Area

Don't miss the **Baltimore Community Group Meeting**, Saturday, December 1, 2007 - 10:00 AM in Baltimore.
See Page 2 for full details.

relieve those symptoms. The great advantage of VSED is that it is a legal and ethical choice that any competent person can make to hasten dying when their suffering cannot otherwise be relieved. The decision can be made privately with loved ones and without medical 'permission' or technical equipment. C&C volunteers work closely with the client and family to ensure that this process unfolds in a thoughtful and well-planned manner, and the client is well supported by hospice and other care givers, so that a peaceful, gentle death occurs where most people want to be: at home, with loved ones.

VSED (continued from Page 2)