

Compassion & Choices of Northern California Newsletter

Fall 2009



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Photo courtesy: Forest Wander

Our End-of-Life Program Fosters a Peaceful, Dignified Death

California's End-of-Life Coordinator, Carole van Aelstyn, supervises Compassion & Choices' volunteers, but often works with clients herself. She wrote the following to illustrate the one-on-one work we do, and to explain why she loves her job.

In June, I received a call from a woman inquiring about our services for her 84-year-old mother. Lynn (name changed to protect privacy) had been told by her oncologist, "There's nothing more I can do for you." Within a week, I made a home visit with Lynn, her daughter, son, and the son's wife. I was shown a stack of medical records that dated back for years. Lynn was alert, but very weak. We discussed all of her end-of-life options, including hospice. Days later her daughter got a hospice referral from Lynn's physician; and services were in place when I visited again a few weeks later.

Lynn and her daughter were present, with her son on speakerphone. Lynn handed me the aid-in-dying letter I had requested. Her children agreed

to Lynn's wishes to hasten her death the next week. I reviewed with Lynn the procedure she would use, and promised to be with her at that time. The following are excerpts from Lynn's letter to me: "I want it to be known that I do not wish to suffer the ravages of my terminal cancer any longer. My current condition precludes participation in any of my beloved life activities. I can no longer focus sufficiently to read, I fall asleep within five minutes of starting to watch TV, I can no longer drive, walk, or even go for a car ride. Visits from family and friends are all too brief because I have no stamina to be social. I need 24/7 caregivers.

I have always been quite independent and my situation is deeply disturbing to me. I am sleeping the majority of the day and growing weaker. I find eating to be a chore and have no appetite. I cannot taste my food and it brings me no satisfaction or enjoyment. Breathing has become labored and even with the wonderful pain management from

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hospice, I still experience shooting pains and tremors throughout the day. The medications given to help me also dull my mind and to me this is the ultimate indignity. I have lived a full and long life despite battling multiple cancers for 20 years. No one can claim that I didn't do everything possible to live as long as possible. My cancers have claimed my life, but not my determination to decide when I would prefer to end my suffering."

I arrived at Lynn's home around dusk; she was asleep in her bedroom. Her daughter, son, his wife, and their adult daughter were gathered in the living room. Lynn aroused easily, and smiled when she saw me. I asked her if she still wanted to hasten her death, and she vigorously nodded "yes". I left the room so she could say her last goodbyes to family. Minutes later her son came out. "She said, 'I want to die now. Bring me the medicine'." Her daughter softly rubbed her back while Lynn spooned in the medication that she had acquired herself. Within a few minutes, she was sleeping peacefully; two-and-a-half hours later, Lynn was dead. She had not moved since ingesting the medication: a very peaceful death.

I love empowering people to make difficult decisions based on their values. When I counsel terminally-ill people, I am honored to be a non-judgmental sounding board, and to work within the law to help clients meet their goals. I get to meet and share intimate time with the most thoughtful, life-loving people and I'm always impressed by the support shown by their families.

To get in touch with the End-of-Life Consultation Program, please call our toll free number 1- 800-247-7421.

Awareness-Raising Luncheon: November 5 at St. Francis Yacht Club

The *Passages* Luncheon on November 5 is not specifically a fundraiser, although co-chairs JaMel Perkins and board member Merla Zellerbach expect to come out in the black. "We're calling this an awareness-raising luncheon," says Merla. "We hope to reach people who've never heard about us but who believe in our cause – junior citizens who may have older relatives, senior citizens who face their own mortality, and everyone in between who believes that thinking ahead and planning for the future pay off."

Senator Dianne Feinstein and Charlotte Mailliard Shultz have graciously agreed to be Honorary Chairs, and are hoping to be there if they are in town. The luncheon will start promptly at noon, with board co-chair Stewart Florsheim welcoming the guests. Board member Fran Johns will introduce a moving video about a terminally-ill woman who approached us for assistance.

After the video, Stewart will lead a panel featuring three experts: board co-chair Jordan Posamentier, Esq.; Dr. Robert Brody, UCSF Clinical Professor of Medicine, Chair of Ethics Committee, SF General Hospital; and Carole van Aelstyn, BSN, Compassion & Choices Client Support Coordinator for California. The panel will answer audience questions, and the luncheon will end at 1:30.

The venue will be the St. Francis Yacht Club "on the Marina." The event is open to all – with limited seating. Admission is \$100, \$60 of which is tax-deductible. Anyone interested should contact Outreach Coordinator Christina Goodwin (admin@compassionandchoicesnca.org, 866-825-8967) and/or send a check to CCNCA, 3701 Sacramento Street #439, San Francisco CA 94118. Your name and ticket will be held at the door. Please come and learn more about our crucial cause.

Art of Comfort and Joy: A Big Success

On May 28, Compassion & Choices of Northern California sponsored "The Art of Comfort and Joy: A Tribute to End-of-Life Care Providers." The event, held in Piedmont, honored organizations and individuals involved in end-of-life care. The evening also included the awards ceremony for the winners of the "Matters in Life and Death Scholarship Writing Contest" (related article on page 3). The providers who were honored, gave short presentations, and were preceded by a poetry reading. The highlight of the evening was a performance by the Threshold Choir, a nationally-known group led by Kate Munger that sings at the bedsides of the terminally-ill. The choir has groups around the country. For more information, please visit <http://www.thresholdchoir.com>.

Matters of Life & Death Scholarship Writing Contest



Co-Chairs Stewart Florsheim and Jordan Posamentier with first place winner Arunima Rashidee.

2009 marked the second year of our scholarship contest for college-bound eleventh and twelfth graders in California. The contest's goals are to expose students to aid-in-dying issues and to financially assist college-bound scholars. The contest was a huge success with over 400 essays received. Prizes of \$1,000, \$500, and \$250, were awarded to first, second, and third place winners, respectively, for originality of thought, as well as clarity and quality of presentation. While writers were invited to respond to one of several prompts, our top three winners responded to:

Why should California legalize the right for terminally-ill patients to end their lives in a humane and dignified manner? Be sure to consider arguments against aid in dying. You may want to reference Oregon's Death with Dignity Act or Washington State's newly passed Aid in Dying measure, Initiative 1000. Both laws permit terminally-ill patients, under proper safeguards, to obtain a physician's prescription to end life.

Gabriel Fierro, a twelfth grader from Santa Rosa, won third place. Our second place winner was Devin Finzer, a twelfth grader from Orinda. And our first place winner was Arunima Rashidee, a twelfth grader from Pleasanton who is attending UC Santa Barbara this fall. She read her winning submission at "The Art of Comfort and Joy" event on May 28 in Piedmont.

We want to share our enthusiasm with you, so we have posted the winners' entries online at www.compassionandchoicesnca.org/essay.php.

To entice you to read the winning entries in their entirety, here are the first two paragraphs of Ms. Rashidee's winning essay:

"Every man has the right to risk his own life in order to preserve it. Has it ever been said that a man who throws himself out the window to escape from a fire is guilty of suicide?"

The right to die is in keeping with famed philosopher John-Jacques Rousseau's idea of self-preservation at the cost of death. Many terminally ill patients would consider their diseases to be analogous to Rousseau's "fire," with the right to die acting as a "window" for escaping an awful situation. Although opponents of the right argue that it shows disrespect for life, the opposite is true. By allowing patients the right to die in a humane and dignified manner, California would be showing respect for the decisions and values of the terminally ill. Because they lack this right legally, Californians are essentially being denied their right to autonomy.

Area Meetings Held Throughout Bay Area

Implementing a new policy designed to reach more members, CCNCA recently held open meetings in Portola Valley and Rossmoor (in Walnut Creek). Advisory Council members Alan and Betsy Carpenter hosted "New Developments and Critical Choices" at The Sequoias, in Portola Valley, on May 31. After a brief reception, board member Fran Johns showed the video "Fran Ravel's Farewell." Betsy and Alan then spoke about the End-of-Life Consultation services and advance care planning. The Rossmoor meeting, "Matters of Life and Death", was held July 15 at the Walnut Creek retirement community. It was hosted by Doris Kagan, who is working to start a Compassion & Choices group at Rossmoor. Fran showed the Ravel video, and co-chair Jordan Posamentier, Esq. updated everyone on the status of death-with-dignity legislation.

If you are interested in knowing more about the Rossmoor group, or would like to host a meeting in your community, contact Outreach Coordinator Christina Goodwin at 866-825-8967 or send in the enclosed remit envelope with a note expressing your interest in hosting a local meeting.



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Medicare Bill Coding for Voluntary End-of-Life Conversations



The fight to pass the advance care planning consultation amendment to Medicare is ongoing. Although medical practitioners hold end-of-life consultations

with their patients now, Section 1233 of House of Representatives Bill 3200 is important because it would authorize Medicare to reimburse practitioners for holding those consultations.

Without end-of-life consultations, terminally-ill patients and their families tend to experience greater distress, lower quality care, and tougher bereavement adjustment.

Compassion & Choices is advocating for Section 1233's passage and is aggressively combating some of the claims made against it. To shed some much needed light on the situation, Section 1233's end-of-life consultations would include the following:

- ◆ An explanation of advance directives and what a

healthcare proxy does;

- ◆ A list of resources to help patients and their families with advance care planning;
- ◆ An explanation that palliative and hospice care is available under Medicare;
- ◆ An explanation of orders on life-sustaining treatment;
- ◆ Why orders on life-sustaining treatment are beneficial to a patient and the patient's family, and why they should be updated periodically as the health of the individual changes

Sorry – no death panels.

Section 1233 took a serious hit when the Senate Finance Committee declined to include its language in their bill. Thankfully, the House's version of the bill, which passed out of three committees, still contains the language. After the House and Senate pass their versions of health reform, the bills go to conference committee where Congress will reconcile the differences and decide to keep or omit Section 1233.