C&C Connection

The Newsletter of Compassion & Choices of Washington

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Medicaid Hospice Benefit Preserved...For Now

When Governor Gregoire included the elimination of Washington's Medicaid hospice benefit in the cuts she announced last August, it sent shock waves through the end-of-life community.

The people most affected by the cut would be low- or no-income people between the ages of 18 and 65. Elimination of the benefit would significantly increase suffering for many young people in this category who need end-of-life care.

Thanks to quick action and effective advocacy by the Washington State Hospice and Palliative Care organization (WSHPCO), support from Compassion & Choices of Washington (C&C), and compelling evidence that eliminating the Medicaid hospice benefit would cost the state more in the long run, the Governor was persuaded to remove Medicaid hospice from the list of proposed cuts. But the fate of the benefit is ultimately in the hands of the Legislature, which could still eliminate it during the 2011 session.

Because C&C believes that hospice is an essential component of end-of-life care, we are partnering with the WSHPCO to educate our legislators about the importance of preserving the Medicaid hospice benefit during the current legislative session.

C&C is issuing a call to action, and your advocacy is needed now. For information about how you can assist the effort, see the instructions on the last page of this newsletter, and then take action. **Be an advocate for terminally ill patients in Washington!**

Death With Dignity Essay Contest

for Students 18 years old and younger

1st place: $1,000 2nd place: $500 3rd place: $100

C&C was honored to receive a generous contribution to underwrite a youth essay contest. The point of this contest is to encourage young people to think about the complexities of choice at the end of life. C&C will not give preference to a "pro" or "con" stance, but to substantiated arguments and well-written prose.

The Death With Dignity Act has been in effect since March 2009. Suggested topics include:

- What impact do you think it has had in Washington? What impact has it had on you?
- What challenges do you see in passing Death With Dignity legislation in other states?
- A related topic of your choice (with approval from C&C prior to submitting the essay).

Essays should be double-spaced, 2000 words or less, on numbered pages, and include a bibliography. Please include a separate cover sheet with your name, age, address, phone number, e-mail address, and the title of your essay. All writing must be original, and quotes should be clearly marked. **A signed parental release form must be submitted with each essay.** For the release form or more information, email mlevy@compassionwa.org. The deadline for entries is March 31, 2011.

All submitted essays become the property of C&C and may be displayed, in whole or in part, in newsletters or other publications and on our website. Submitted essays will not be returned.

Jee-Ihin "Jay" Lee, Policy & Advocacy Intern and Jibril Ahmed, High School-Age Volunteer.

The Robb Report

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Compassion & Choices of Washington provides this newsletter to you as part of our educational outreach. If you would like to help defray publication costs, donations are gratefully accepted.

If your name is printed incorrectly, you wish to stop receiving the newsletter, or you are receiving duplicate copies, please let us know.

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Our last newsletter, which included a front-page story titled "Catholic Directive Undermines End-of-Life Choices," created quite a stir. A few of my peers who are employed by Catholic health systems let me know exactly how they felt about it.

Robb Miller,
Executive Director

In this story, I raised questions about whether Washington's Catholic health care providers would honor patients' advance directives related to declining medically administered nutrition and hydration following recent changes in the Catholic Ethical and Religious Directives (ERDs).

Since we published the story, physicians and other medical providers I know, respect, and trust have assured me they are honoring patients' advance directives, including provisions about nutrition and hydration. I also met with representatives from a Catholic health system who have direct knowledge about enforcement of the ERDs. I now have a much better grasp of the complexities of Catholic health care dogma vs. actual medical practice in Washington.

I also came away with a clear understanding that the local bishop sets the tone. Perhaps because our Pacific Northwest Catholic congregations lean progressive (nearly 50 percent of Catholic voters were in favor of the Death With Dignity Act in 2008), we have been blessed with less conservative bishops.

Although I will remain openly critical of Catholic health care providers' patriarchal, antichoice policies related to Death With Dignity, it was not my goal to sow unnecessary fear about whether advance directives would be honored or to undermine patients' trust in their physicians and other medical providers. Some of the best palliative and hospice clinicians in Washington work for Catholic providers, and many of them are fierce advocates for patients' rights at the end of life. I apologize for any anxiety my story may have created or negative impacts on Catholic health care providers.

Now that we have a new bishop in Western Washington, and there is a new, much more conservative president of the U.S. Catholic Council of Bishops, we will be watching very closely to see if the current climate concerning enforcement of the ERDs that affect advance directives changes in Washington. If it does, I promise that you will be among the first to know. Conversely, if you know of any instances when advance directives are not being honored or were not honored, please let us know.

Health Care Decisions IQ Test

For Family, Physician, or Health Care Agent

How well does your family, physician, or health care agent know your health care wishes? This short test can give you some sense of how well you have communicated your wishes. Consider this a tool to promote conversation and increase the likelihood that your end-of-life wishes will be honored.

Instructions:

1. Make as many copies as needed, one for you and everyone you want to take the test. Save this original, if desired, so that you can use it in the future.
2. Answer the questions yourself and don't reveal your answers.
3. Ask your family member, physician, or health care agent to take the test. They should answer the questions in the way they think *you* would answer.
4. Compare your answers to test taker's answers. Count one point for each question on which you and the test taker gave the same answer. Their Health Care Decisions IQ is rated as follows:

- **5 points** = Superior; you have done a great job communicating your wishes.
- **4 points** = Good, but you need some fine-tuning.
- **3 points** = Fair, but more discussion is needed.
- **1 or 2 points** = Poor; you have some talking to do.

1. You are 91 years old and have been in failing health for a few years. You spend most of your day in bed and you need care 24 hours a day because of your dementia. You easily forget who your friends and family are when they come to visit. You have begun to lose interest in eating, and you have lost a lot of weight. You are physically comfortable and generally in good spirits. The doctor is talking about a feeding tube so that you can get adequate nutrition. *Would you want the Feeding tube?*

a. Yes **b. No** **c. Uncertain**

2. You have late-stage Alzheimer's disease and can neither recognize nor converse with your family or other loved ones. You been diagnosed with pneumonia that will become fatal unless it is treated with antibiotics. *Would you want antibiotics?*

a. Yes **b. No** **c. Uncertain**

3. You have been found after having a heart attack, and you have no heartbeat and are not breathing. Emergency medical providers revive you, and you are now in intensive care, unconscious, and connected to a breathing machine. After a few days of tests, doctors know you were deprived of oxygen to the brain for several minutes during the heart attack, and you have brain damage. Your doctors do not think you will wake up. If you do, you may eventually be able to get off the breathing machine, but it's likely – although not certain – that you will need help with everything, including dressing, eating, and toileting. *Would you want the breathing machine continued?*

a. Yes **b. No** **c. Uncertain**

4. You have congestive heart failure that causes your lungs to fill up with fluid; your health is poor; and you are unable to walk around one block. You are always short of breath and tired all the time, but you are alert and able to enjoy time with family and friends. One day you have a heart attack and your heart stops beating. *Would you want CPR started and 9-1-1 called?*

a. Yes **b. No** **c. Uncertain**

5. You have advanced liver cancer that has spread to your bones and internal organs. You are at home and receiving hospice care. You cannot leave your bed or move too much because activity increases the pain, which, despite large doses of pain medication, is getting worse. You are so heavily medicated that you are in and out of consciousness, but, when you are conscious, you can still recognize and talk to your family. The hospice nurse has offered something called palliative sedation to manage your pain, where you would be sedated to unconsciousness for the rest of your life, but your family must approve it. *Would you want palliative sedation?*

a. Yes **b. No** **c. Uncertain**

C&C Welcomes Two Spiritual Leaders to the Board of Directors

Richard Gibson, MDiv

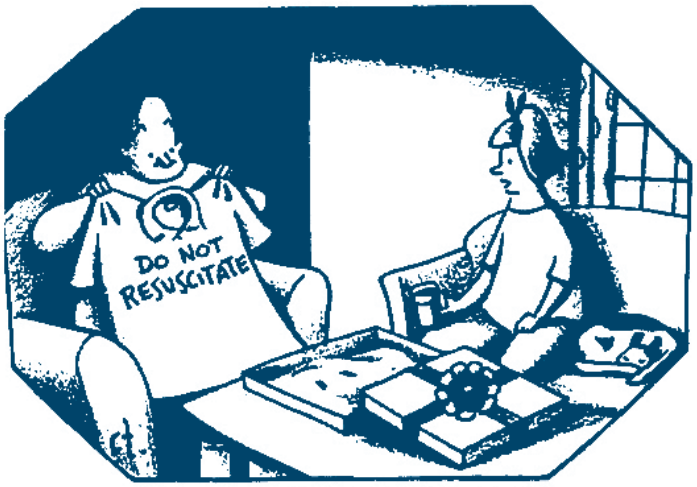
Rev. Richard Gibson retired following 30 years of ministry as the pastor of Terrace View Presbyterian Church in Mountlake Terrace, Washington. He has been active in several community programs, including Peace Action, a grassroots organization opposed to war and violence. He also serves on two committees of the Presbyterian Church: one welcoming gay and lesbian people into full participation in the life of the church and another working to help Palestinians achieve justice and peace. Dick established the Mountlake Terrace food bank and is currently on the board of the Snohomish County Food Bank Coalition. In his spare time, he teaches classes on religion, archaeology, and the Bible at different churches and the Creative Retirement Institute of Edmonds Community College.

When asked why he chose to volunteer for C&C, Dick said that "as a pastor, I have been at the side of the dying and their families from the beginning to the end - during good deaths and bad deaths. C&C provides information about choices that provide dignity and comfort to people when it's most important. The work of C&C resonates with my theology about human life."

Rev. Patricia Simpson is the Seattle District Superintendent of the Pacific Northwest United Methodist Conference and a Northwest native. Her pastoring experience has taken her all over western Washington, from very small towns to downtown Seattle, where she was the pastor at a church for homeless and formerly homeless women.

Patricia Simpson, MDiv

When asked what inspired her to join C&C's board, Pat stated that "as a pastor for over three decades I walked beside a lot of dying people and their families. Even with good end-of-life medical care, some people suffered terribly in their last days. Some patients and family members shared deep questions of conscience about whether prescribed medications should be used to hasten death. This was pre-2008. None of them had the legal option of Death With Dignity. I can imagine those same conversations now. They would still be difficult, but no longer shadowed by secrecy or fear of prosecution. Open dialogue with doctors, support from a C&C volunteer, and confidence that the medication will work – all these things could smooth the road for a careful, prayerful, and confident decision. It might be yes, or no, but freely made. The freedom to act as stewards of our own lives should be accessible to us all."



IF YOU DON'T LIKE THE PINK, IT COMES IN 16 OTHER COLORS.

Are you a good listener?

Become a Client Support Volunteer!

Client Support Volunteers are currently needed in all parts of Washington except Seattle. If you are looking for a fullfilling volunteer opportunity, contact us today. For more information, visit our website, and click on "Get Involved."

Introducing Our New Client Support Volunteers

Seattle

Sarah Berry, PhD, teaches philosophy at Seattle University. One of her courses is Health Care Ethics, which addresses the issue of aid in dying. Sarah was introduced to C&C many years ago when she invited C&C Executive Director Robb Miller to speak to her class. Now that Sarah's daughter is a teenager (and Sarah has a bit more time), she has decided to move from the theoretical aspects of Death With Dignity to the practical as a C&C client support volunteer. Sarah is currently writing a paper on Hegel's theory of autonomy and the relationship between the Death With Dignity client and the C&C volunteer. She plans to apply to the Masters of Nursing program at Seattle University later this year. In her free time she enjoys reading, gardening, skiing, and backpacking.

Spokane

Hal Holte, MD, is a retired radiologist who became interested in end-of-life issues through interaction with his patients during his many years in practice. Since his retirement, he has also volunteered with Hospice of Spokane. Hal says he strongly believes that people need to have choices when making end-of-life decisions. He adds, "I continue to be amazed at the grace and equanimity with which people deal with dread diseases and impending death. I learn something valuable from each and every one of these individuals. I believe it is an honor to be allowed to participate in the lives of those in need." Hal also enjoys hiking, fly fishing, bicycling, vegetable gardening, and cooking.

Seattle

Bill Logan, MS, CMD, moved to Washington from Maine four years ago. He admires the natural beauty of the Northwest and loves to ski and hike. Bill holds a masters degree in biophysics, and works as a medical dosimetrist (calculating the dosage of radiation) in radiation oncology, where, in addition to curative treatments, a lot of palliative procedures occur. Bill states, "Seeking treatment and choosing to fight is a very individual choice. I respect everyone's choice to do so." He believes that earlier discussions about hospice and other options would improve the quality of life for patients facing the dying process but observes these conversations do not always happen. Bill is honored to help facilitate these discussions by volunteering for C&C.

Research Underscores the Importance of Early Conversations about Dying

A study in the *Archives of Internal Medicine* about health care costs in the last week of life concludes that patients with advanced cancer who reported having end-of-life conversations with physicians had significantly lower health care costs in their final week of life. **Higher costs were associated with worse quality of death**. *(Arch Intern Med. 2009;169(5):480-488)*

Patients with cancer are **more likely to receive end-of-life care that is consistent with their preferences** when they have had the opportunity to discuss their wishes for end-of-life-care with a physician, concludes a recent study in the ***Journal of Clinical Oncology***. *(J Clin Oncol 28:1203-1208)*

In a study that sheds new light on the benefits of palliative (comfort) care, doctors found that patients with terminal non-small-cell lung cancer who began receiving palliative care immediately upon diagnosis **not only were happier, more mobile, and in less pain as the end neared – but they also lived nearly three months longer**. (*N Engl J Med 2010;363:733-42)*

For advice about how to communicate effectively with your physician or family, download our documents *Talking to Your Family About Dying* and *Talking to Your Doctor About Dying* from our website, www.CompassionWA.org (click on "Resources," then "Documents You Can Use"), or call our office to receive them in the mail.

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In This Issue

Medicaid Hospice Benefit	1
DWD Essay Contest	1
Robb Report	2
Healthcare Decisions IQ Test	3
New Board Members	4
New Client Support Volunteers	5
Recent Research	5
Maintain Medicaid Hospice	6

Three Ways You Can Help Maintain Medicaid Hospice in Washington

1. **Call the legislative hotline, 1.800.562.6000, and leave a brief message for your legislators** telling them to maintain the Medicaid Hospice and Medicaid Adult Pharmacy Benefits, and that eliminating these benefits is not a solution to the budget deficit because it's a cost shifting, not a cost savings. When leaving a message with the hotline, be prepared to give your name and street address (home, not work). The hotline hours at 8 a.m. – 8 p.m., Mon. – Fri., and 9 a.m. – 1 p.m., Sat.

2. **Send an email or letter with the message above to your legislators.** If you have internet access, you can find your legislators or their contact information at http://apps.leg.wa.gov/districtfinder/default.aspx. Or call our office: 206.256.1636 or 1.877.222.2816 toll free.

**ADVOCACY DAY IS FULL!

3. **Join Us In Olympia at 7:30 a.m. on February 23 for 2011 Hospice Advocacy Day.** This year we are joining forces with Washington State Hospice and Palliative Care Organization and the Home Care Association of Washington to make certain that all our senators and representatives understand the positive financial and social impact of the Medicaid hospice benefit in order to protect it from future cuts. An orientation will be provided and all visits will be done in small groups pairing experienced advocates with those who are new to the process. Your involvement is important as we can only schedule visits if we have a district constituent with us. There is no cost but **registration is required.** For more information or to register, go to www.wshpco.org and follow the instructions on the homepage, or call our office.

**Please use options 1 or 2 to advocate for Medicaid hospice, or you can always visit Olympia at your leisure and speak to your legislator in person (call ahead to try to schedule an appointment).