

Non-Profit Organization
US Postage
PAID
Seattle, WA
Permit #1896

Death With Dignity in Washington: Safe, Legal, and Rare

C&C has helped nearly 85 percent of the patients who have used the Washington Death With Dignity Act (DWDA). Approximately 30 percent of our clients who received the medication opted not to use it. Many have said that just having the medication and knowing that the option is available provides them with great comfort.

If you are terminally ill and want the option to use the Death With Dignity Act, don't wait to call C&C.

Like Oregon, many of the patients seeking to use the law are white, college-educated persons. Men and women are equally likely to pursue this option and see it through. The most frequent diagnosis is cancer. Loss of autonomy is documented as the most common reason people opt to pursue DWDA, followed by being less able to engage in activities that make life enjoyable, and the loss of dignity. Almost all of our clients who used the law were on hospice.

The primary difficulty that we are facing as the steward of the DWDA is that some patients wait too long to call us. It generally takes between 15 days to a month for qualified patients to receive life-ending medication. Several of our clients died within a week of calling to arrange for a volunteer. If you are terminally ill and want the option to use the DWDA, don't wait to call C&C. Conversations with your physician about whether or not she or he will participate can, and should, happen before a terminal diagnosis occurs, and we can provide a "letter to my physician" to help you expedite this conversation.

C&C's longtime Medical Director, Tom Preston, MD, has networked with physicians statewide to educate them about DWDA and provide them with the medical protocol and Department of Health paperwork

WA Department of Health's (DOH) DWDA Statistics

		Notes
DWD Prescriptions Filled	49	Some people who have completed all the requirements wait to have their prescription filled or have the pharmacy hold it.
Psychiatric Evaluations	3	The number of "failed" psych evaluations is not tracked – only those who pass. Therefore, the DOH's website and upcoming annual reports will not reflect the true number of those who receive psych evaluations.
After Death Forms Received	32	Reflects the total number of patients who died after receiving a prescription for life-ending medication but does not differentiate between those who did and didn't take life-ending medication. The breakdown will be available in the DOH's 2009 annual report.

IN THIS ISSUE	
Death With Dignity Update	1
An Idea Whose Time Has Come	2
Academic Research	3
Advance Directives Comparison	4
Board President Reelection	6
Sequim's Champion For Choice	6
Two Decades of Volunteering	7

Daughter of Washington's First Death With Dignity Patient Takes Editor of LifeNews.com to Task

The daughter of Linda Fleming, the first person to use the Washington Death With Dignity Act, wrote the following to Steven Ertelt, editor of the antichoice website, LifeNews.com:

I realize that your publication has an agenda to push, but your statement, "Linda Fleming... did not want to suffer and become a burden on her family," is incorrect. My mother never was concerned about becoming "a burden on her family." Nowhere has she been quoted saying this, and nowhere has it been so written. I want to be charitable and assume that you have made a simple mistake and did not intend to put words in my mother's mouth, impugn, or libel my mother or our family. Nevertheless, it is offensive, and our family demands a retraction and an apology.

Lisa T. Osborne
Daughter of Linda Fleming

Mr. Ertelt replied: "We already changed this." [No apology was offered.]

The Robb Report

BOARD OF DIRECTORS

Terry Barnett, Esq., *President*
Joanne Brekke-Salk
Sheila B. Cook, *Editor*
Alberta Golden, *MLS*
Judith Gordon, *PhD*
Arlene Hinkley, *ACSW, Secretary*
Widge Levy, *ACSW, Vice President*
Catherine L. Longhi
Bruce Parker, *DMin*
Thomas Preston, *MD*
B. Kirk Robinson, *Treasurer*
Thomas Smith, *MD*

ADVISORY COMMITTEE & MEDICAL ADVISORS

Michael Bonacci, *MFA*
Fred Ellis, *PhD*
Robert A. Free, *Esq.*
Jonathan Gavrin, *MD*
Steven Ginsberg, *MD*
Molly Hoffman, *MSW*
Trudy James, *MRE*
Len Mandelbaum, *Esq.*
Rusty Myers, *MSW*
Paul V. O'Donnell, *MD, PhD*
William O. Robertson, *MD*
Fred Simons, *PharmD*
Patrice C. Smith, *CPA*
Virginia Stout, *MA, PhD*
Doreen Tarr, *CA*
Jinny Tesik, *MA*
Mary Watson, *LPN*
Robert W. Wood, *MD*

STAFF

Robb M. Miller, *Executive Director*
Amber Wade, *Director of Client Support*
Sean Stearns, *Graphic Design/Web*

Office Volunteers

Norma Beerweiler
Wendy Clark
Kristin Kennell
Iona Stenhouse
Gayle Yamamoto

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.

Printed on recycled paper.



In this newsletter, our guest columnist is the president of the national organization, Barbara Coombs Lee, whose recent Huffington Post blog was just too good not to share with our readers. – Robb Miller, Executive Director

AN IDEA WHOSE TIME HAS COME

Sometimes a movement's opposition is its best friend. And an opposition commentator is the first to tell the world transformative social change is underway.

A recent National Review cover story warns of a dangerously potent cultural shift. It seems Americans are moving out of frank denial and blind fear of death into a position of empowerment and choice in our end-of-life experiences. This is a bad thing, from National Review's perspective.

"No army can withstand the strength of an idea whose time has come."
- Victor Hugo

The article bemoans a "creeping culture" of suicide and euthanasia. Of course those are their inflammatory words to describe the emerging culture. Our words would be that a culture of dignity, human liberty, and personal choice is finally gaining ground.

On the way to arguing against us, the National Review makes some keenly perceptive observations. First, the author acknowledges our movement has "come a long way" in twenty years, and credits Compassion & Choices as the "premier advocacy group" to make that happen. He deplors that today members of "the social and political elite" readily voice their support. And he opines that when they do this "as openly as they would with charities like the United Way, we have reached a new cultural moment."

Hooray for that! I, too, sense that human mortality is no longer the political third rail it used to be. For all the "death panel" hysteria this August and September, those charges never did really get any traction. And the fear-monger politicians peddling "kill granny" hyperbole have joined those who embarrassed themselves a few years ago by elbowing their way into the Schiavo family tragedy. They just look silly, opportunistic, and mean.

The author also acknowledges our movement's recent successes and calls 2008 a "banner year." Finally, he writes that as individuals, we are "passionately committed, work hard, and feel time is on [our] side." All true, and we are truly grateful for the praise!

As one might expect, the writer opposes personal choice in most important life decisions. A believer in intelligent design, he opposes stem-cell research and choice in dying. The vigor of his opposition highlights the power of end-of-life choice to move society to a new level of respect for personal autonomy and human dignity. His intense focus tags our movement, with Compassion & Choices in the lead, as an especially potent force for liberty.

(continued on page 7)

AN IDEA WHOSE TIME HAS COME (from page 2)

Social progress takes concerted, sustained effort. For fifty years individuals and foundations concentrated on the key issues of civil rights, equality for women and reproductive choice, to promote human dignity and liberty. Equal opportunity for women and minorities, together with reproductive freedom, were the dominant fields of battle for twentieth century struggles around human dignity, individual autonomy, and self-determination. Now, at the dawn of the twenty-first century, new battle lines are drawn between patients who struggle for control over unnecessary suffering at the end of life and authoritarians who would keep control elsewhere.

The opposing forces remain essentially unchanged from last century to this. Individuals asserting their own values and beliefs seek control over important decisions in their lives, especially healthcare decisions. Dogmatic churches, autocratic institutions, and authoritarian politicians fight to limit individual authority over self.

Who decides if a couple can purchase birth control

Frans Wery, MD & Else Mans, MD:

Frans Wery, MD, became a Client Support Volunteer for C&C in 1997, after retiring from Group Health Cooperative, where he practiced medicine for 30 years.



As an emergency medicine physician, Frans witnessed many situations when the family of a dying patient was unrealistic about what would be gained by using extreme medical interventions to keep the patient alive. "Often the patient was ready for death, but the family and medical providers weren't ready to let go or give up." His work-related experiences and issues raised by the Initiative 119 campaign inspired Frans to become more involved, and that led him to C&C.

During the 11 years that Frans volunteered, he supported and empowered dozens of our clients through the dying process, ensuring they were able to have humane, peaceful deaths on their own terms. He also mentored many new client support volunteers. While the role was challenging, Frans says that "the gratitude and appreciation of the patients and their families sustained me."

Now that the Death With Dignity Act is in place, Frans feels this is a good time to stop volunteering and spend more time with his family and in his garden on the shore of Lake Sammamish.

devices? The most powerful church in the world wants to decide and, until 1965, enlisted states to enforce bans on contraceptives.

Who decides whether people may opt for treatments developed through stem-cell research? Right-to-life organizations decide and enlist Congress to keep federal money away from scientific breakthroughs.

Who decides whether dying patients may ask their doctors to help them experience a humane and peaceful death? The American Medical Association decides, and uses its formidable political power to pressure lawmakers into ignoring the will of the people.

End-of-life choice is the human liberty movement of the twenty-first century. This is the arena where dignity and liberty stride forward today. People who care about core principles of justice and human dignity feel drawn to this movement. The struggle for end-of-life choices is a movement whose time has come.

More Than Two Decades of Service

Else Mans, MD, began volunteering in 1999, joining her good friend, Frans Wery, MD, who became her mentor while she learned to be a client support volunteer.

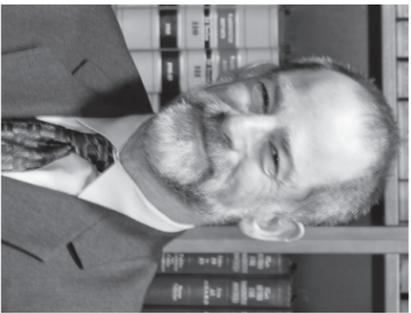
Else was educated and trained in the Netherlands and had an interest in patient-directed dying from the time of her medical internship. In her early practice as a family physician, she often found herself in a supporting role to her dying patients. Ultimately, Else moved from family medicine to psychiatry.

Volunteering for C&C was a natural fit for her interest in providing support to the terminally ill. Due to her medical and psychiatric expertise and her uncanny ability to "get to the heart of issues," Else was a remarkably effective client support volunteer. Over the years, she helped many of our clients overcome very difficult or complicated situations.

After 10 years of dedicated service to our clients and C&C, Else has decided this is the right time to stop volunteering. She spent this past winter in New Mexico and intends to go back for the winter months. We think she's earned the right to be a snowbird!

For their commitment to our mission, their 21 years of combined service to our clients and their families, and for being Washington's pioneers for choice at the end of life, we express our deepest gratitude and appreciation to Else and Frans.

Terry Barnett Begins Second Term as C&C's Board President



Terry Barnett has long advocated for patients' rights at the end of life. During his law practice, he counseled and represented many clients in legal matters involving withholding and withdrawing life-sustaining treatment. He has also served on several hospital ethics committees and authored *Living Wills and More*, a comprehensive guide for advance planning.

His involvement with C&C grew out of his end-of-life experiences, both personal and professional: "There was so much pain and confusion for everyone – patient, family, doctors, and caregivers. I felt there must be a more humane solution."

Terry has been a member of C&C's board since 1997. During his first term as board president, he was at the helm when C&C's board agreed to create the coalition that created the I-1000 coalition. "I was always hopeful that I-1000 would win, but I didn't expect it to win by such a wide margin. That was very gratifying." He was also pleased by the geographic distribution of the favorable vote (I-1000 won in all but nine counties). The vote showed "the depth of feeling people have regarding the issue of personal liberty and their belief in having control of their lives."

Terry retired from his law practice in 2007. He is a dedicated father to his two very active daughters who are 10 and 17 years old. In his "spare" time, he is learning to play the baroque flute and practices yoga.

Dawna Zullo: Sequim's Champion for Choice at the End of Life

Dawna Zullo has the distinction of being the client support volunteer for the first three patients who used the Washington Death With Dignity Act (DWDA). She was at Linda Fleming's side when Linda became the first person to use the DWDA.

Dawna was drawn to volunteer for C&C after attending a lecture by C&C's executive director, Robb Miller, in Port Townsend in 2003. She responded immediately to the ideas he expressed and became a client support volunteer.

Dawna purposely selected Sequim as her home base seven years ago. She had been living in Utah but felt she needed to find a home that had natural beauty as well as a supportive community. When she visited Sequim, she knew "this was my place." When she's not volunteering for C&C, Dawna is a fitness buff and avid birdwatcher.

Her life experiences as a Colonel in the Army, a deputy sheriff, and the personal experience of the death of her mother and sister led her to believe that we should all be able to make choices about the end of our lives.



Dawna finds great fulfillment and satisfaction in volunteering for C&C. She helps her clients advocate for themselves with their doctors and families and informs and supports them as they make end-of-life choices. "Most important," says Dawna, "is being a compassionate listener, which allows people to open up in a way that they can't with their families, friends, or medical providers. My clients know they are dying, but they often have a specific role to play in their family – as a wife or a grandfather. With me, they don't have to fill a role. They can, and do, talk freely about their fears, hopes, and the kind of death they want. It is very rewarding to be there when you are really needed."

Academic Research Upholds Aid in Dying

Death With Dignity has no effect on the grief, depression, or mental health outcomes of surviving family of patients when compared to patients who died naturally of cancer or ALS.

Source: Ganzini L, Goy ER, Dobscha SK, Prigerson H. *Mental Health Outcomes of Family Members of Oregonians Who Request Physician Aid in Dying.* *Journal of Pain and Symptom Management.* 2009 Sep 22.

When the Death With Dignity Act (DWDA) was first enacted in Oregon, considerable debate focused on whether or not vulnerable populations, such as persons of color or patients who were poor or uneducated, would be coerced into participating in the DWDA. The Oregon data demonstrate that this has not materialized.

Source: Hedberg, K., Hopkins, D., Leman, R., and Kohn, M. (2009) *The 10-Year Experience of Oregon's Death with Dignity Act: 1998-2007.* *The Journal of Clinical Ethics* (20), 2: 124-132.



Medical Director Tom Preston, MD, Board Member Kay Longhi, and I-1000 spokesperson Nancy Niedzielski at C&C's 2009 Annual Meeting.



Despite the torrential downpour and power outage, there was a good turnout at the Annual Meeting.



2009 Annual Meeting panel of presenters: Arline Hinckley, Board Member and Client Support Volunteer; Lisa Osborne, daughter of the first patient to use the Washington DWDA; Robb Miller, Executive Director, C&C of Washington; and George Elghmey, Executive Director, C&C of Oregon.

Washington's Living Will Registry: Use it or Lose It

C&C was barely able to save the Living Will Registry from budget cuts during the last legislative session. But if more people don't utilize it, we may not be able to save it from elimination during the upcoming session.

If you haven't registered your advance directives, do it now by going to www.doh.wa.gov/livingwill. It's free and easy. After you register, you will receive a wallet card, and your documents will be available to your family and medical providers wherever there is internet access.

C&C Compares Washington's Most Common Advance Directives

Natural Death Act Healthcare Directive

Pro

- Widely available online or from medical providers at no charge.

Pro or Con

- Simple and concise; only two pages long.

Con

- Limited to terminal conditions only.
- No dementia provisions.
- Not specific enough about what treatments a patient does/doesn't want and when the patient does/doesn't want them.
- Requires an additional document, a Durable Power of Attorney (DPOA) for healthcare, to name a healthcare agent.
- Includes an antichoice statement that many people find objectionable. ("If I have been diagnosed as pregnant and that diagnosis is known to my physician, this directive shall have no force or effect during the course of my pregnancy.")

Notes

- Created by Washington's legislature prior to the existence of C&C (which would have prevented the inclusion of the antichoice statement).
- Most commonly used healthcare directive in Washington; used by hospitals, attorneys, the Washington State Medical Association, Group Health, and many others.
- Vague, outdated, and not recommended.

Grade: D



The Five Wishes

Pro

- Easy to understand, with embedded directions.
- Applies to both terminal and nonterminal conditions.
- Combines the DPOA for healthcare and healthcare directive.
- Provides more details about what treatments a patient does/doesn't want and when it applies.
- Bilingual versions available in 24 different languages.
- Includes dementia and coma provisions.
- Provides space to customize and clarify decisions.

Pro or Con

- Includes a significant amount of nonmedical information (being massaged with warm oils, having your favorite music played, and how you want to be remembered).
- Eight pages long including instructions.

Con

- Costs \$5, and another \$5 for the Next Steps document.
- Wish 2 includes an antichoice statement that can create a profound conflict within the document. ("*I do not want anything done or omitted by my doctors or nurses with the intention of taking my life.*")
- Unless crossed out, states you would want pain medication only to the point of being drowsy or sleeping more than you would otherwise (ruling out palliative sedation for unmanageable pain).
- Inconsistent; asks you to cross out statements you don't agree with under some Wishes, but not others (Wish 2, in particular).
- Designed to prohibit any form of aid in dying.

Notes

- The Five Wishes sponsor, Aging With Dignity, has ties to the Catholic Church, and Five Wishes conforms to the antichoice, end-of-life provisions included in the *Ethical and Religious Directives for Catholic Health Care Services*.
- C&C strongly recommends that users cross out Wish 2 and initial and date it.
- After elimination of its internal conflict, Five Wishes is a good, all-purpose advance directive.
- Available from www.agingwithdignity.org or toll-free 888.594.7437.

Grade: B (With the antichoice statement crossed out)

Grade: F (Including the antichoice statement)

C&C's Advance Directive

Pro

- Applies to terminal and nonterminal conditions.
- Includes several clearly worded dementia provisions.
- Combines the DPOA for healthcare and healthcare directive.
- Uses clear language about what you want/don't want and when you want/don't want it.
- Free; download from our website or by request.
- Available in large-print version.
- Contains no antichoice statements.
- Includes an option for avoiding all life-sustaining or life-prolonging treatment under any circumstances (for the very elderly or people who wish to allow a natural death; e.g., people with Alzheimer's).
- The coma and persistent vegetative state provisions allow you to set time limits.
- Includes a provision for requesting maximum pain and comfort care, even if it might hasten your dying process.
- Affirms your healthcare agents' rights to make a Physician Orders for Life-Sustaining Treatment (POLST) form on your behalf.
- Allows for an additional statement of values.
- Uses very specific terminology to prevent subjective interpretation.
- Instructions include what to do after completing your advance directive.
- Promotes the use of Washington's Living Will Registry.

Pro or Con

- Comprehensive and detailed; a five-page document accompanied by seven pages of instructions.

Notes

- The most appropriate document for those who want to express specific wishes and those who have been diagnosed with dementia or Alzheimer's.
- C&C's advance directive packet includes additional information about advance planning, including how to talk to your family about dying.
- Available from www.CandCoFWA.org or toll free 877.222.2816.

Grade: A