



Year One of the Washington Death With Dignity Act

There were no surprises when the Washington Department of Health released its first annual report on the Death With Dignity Act (DWDA) on March 4, one year after the law became effective. The report shows the law is working as intended, and none of the opponents' predicted abuses have occurred. Death With Dignity in Washington has been safe, legal, and rare.

2009 DWDA Statistics	
Prescriptions filled	63
Died taking DWDA meds.	36
Died without taking DWDA meds.	7
Lived West of the Cascades	94%
White, non-Hispanic	98%
College educated	62%
Concerned with loss of autonomy	100%
Died at home	94%
Died receiving hospice care	72%
Patients supported by C&C	80%



See the full report at http://www.doh.wa.gov/dwda/forms/DWDA_2009.pdf.

At our March 4 press conference, Kathy Sparks, RN, a former hospice nurse with stage 4 Melanoma, tells the media that the DWDA provides her with peace of mind. Photo courtesy of the Issaquah Reporter.

Lessons Learned in Year One

- Terminally ill patients who want the option to use the DWDA should call C&C now, especially if they are living east of the Cascade Mountains.
- Patients reported peace of mind after acquiring life-ending medication. Some have held their medication for months, and some never use it.
- Patients who want the option should find out where their physicians stand on the issue (see Talking to Your Doctor about the DWDA on page 4).
- Patients and families should consider having a C&C volunteer present at the time of a DWDA death to ensure the medical protocol is followed and that no complications occur.
- Patients should expect to pay \$500 - \$700 for the DWDA medications.
- Hospice is always highly recommended, but patients should not expect hospice to help with the DWDA.

Reflections on a Decade

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The first of April marks my ten-year anniversary as the Executive Director of Compassion & Choices of Washington (C&C), and my how things have changed since 2000.

Ten years ago, some hospice folks would not sit at the same table with me. Last week, the medical directors and a clinical director of an excellent hospice *came to our office* and assured us that they didn't stop practicing patient-centered care just because a patient wants to use the Death With Dignity Act (DWDA). Then *they asked us to work with them* by reassuring our mutual patients that they could, and should, let their hospice staff know of their intent to use the DWDA so they can provide the best possible care.

During introductions at the annual meeting of the Washington End of Life Consensus Coalition last October, a newcomer – an antichoice hospice nurse from the so-called True Compassion Advocates (formerly the Coalition Against Assisted Suicide) – stood up and, very politically, said “I’m representing True Compassion Advocates which presents a life-affirming alternative to the DWDA...” People rolled their eyes, looked down at the agenda, and made knowing glances at one another. You get the picture.

In contrast, I have been a member of the Coalition's steering committee for ten years. Additionally, I was one of the keynote speakers and participated on the committee that organized the meeting. Despite the Coalition's policy of not addressing the issue of aid in dying, I have spent countless hours over ten years furthering our common mission to improve end-of-life care in Washington, and the Coalition's members know it.

Most significant of all, and one of the high points of my life, was the passage of I-1000 in 2008. Providing qualified, terminally ill patients with another end-of-life option – one that can provide control, peace of mind, and dramatically improve the quality of life at the end of life – has changed the entire paradigm of end-of-life care in Washington. If the DWDA has the same impact here as it did in Oregon, end-of-life care should improve for everyone.

When I look back on my decade at the helm of C&C, I'm amazed at what we have been able to accomplish together. None of it would have been possible without the committed social justice activists who started the Washington State Chapter of the Hemlock Society in 1988 and founded Compassion In Dying in Seattle in 1993. For 22 years, dedicated board members, the amazing client support volunteers and medical director, and the generous support provided by people like you made it possible for us to uphold patients' rights to excellent care and choice at the end of life. Thank you for your consistent support.

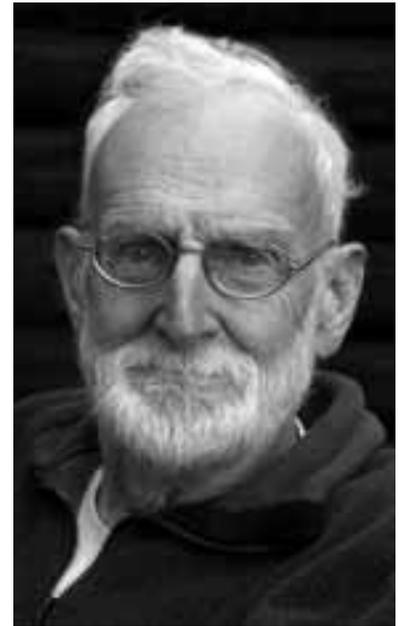
For Robb Miller's recent Op-ed in the Seattle Times about the first year of Death With Dignity, see page 7.

Remembering Fred Ellis, PhD

Fred Ellis, PhD, joined our board of directors in 1995 and served for many years before joining our advisory committee. He traveled from the San Juan Islands to attend our board meetings in Seattle.

Fred was a professor of history and philosophy and an avid astronomer. He was a passionate and effective speaker to academic and community groups and wrote powerful, widely published letters. The following excerpt from a letter published in *The Catholic Reporter* in 1995 illustrates his passion and style:

“...our one and final civil liberty is the choice we can make about how we can exit our earthly sojourn on planet Earth...I do not wish to give up that final civil liberty and turn it over to my physician in a heroic effort to stave off death. Nor do I want to give it up to a church or to the state... Never forget that it took more than 125 years of bloody Protestant revolt to establish the principle of live and let live. The essence of liberty is the freedom of choice in realms each of us deems significant.”



Fred died on February 5 of congestive heart failure at the age of 93. He lived a very rich life of experience, passion, and giving back. In January, it was apparent that he had little time left. He accepted that his heart was failing and reached out to loved ones to let them know they were dear to him. He will be missed by many, and his passion for civil liberties and environmental protection will continue through the work of C&C and others he inspired.

“I’m not even allowed to call it by that name...I have to call it physician-assisted suicide.”

~ Providence Marianwood Foundation Director, Steve Gallion, whose employer bans providers from giving patients the option of Death With Dignity. Marianwood is a Catholic nursing home. As reported in the *Issaquah Reporter* on March 9, 2010.

Antichoice Activists Protest Death With Dignity

The so-called True Compassion Advocates (formerly the Coalition Against Assisted Suicide) protested in front of the UW Medical Center on Thursday, March 5, one year after the Death With Dignity Act took effect in Washington. Approximately 50 people, including many children, took part. Ironically, the group protested at the only major Seattle hospital and medical center that, to our knowledge, has never supported a patient who used the DWDA.

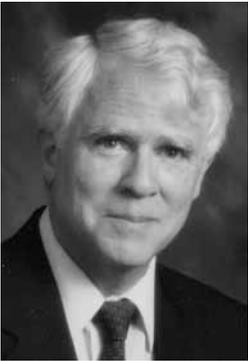


Children at the March 5 protest. The sign on the right states: “The DWDA is a recipe for Edler Abuse.” Photo courtesy of Erika Goldberg.



“True Compassion Advocates” protest your right to Death With Dignity. Photo courtesy of Kristin Kennell.

Talking to Your Doctor About Death With Dignity



Tom Preston, MD,
C&C's Medical Director

The most important lesson we learned from our first year of experience with the Death With Dignity Act (DWDA) is that patients who want the option should not wait to discover their physician's beliefs about the law.

After explaining that you believe in being prepared, and that you would like to make sure that you would be on the same

page in an end-of-life situation, ask your physician directly with specific language: *"If I were terminally ill and wanted to use the DWDA, would you write me a prescription for life-ending medication?"* You need a definitive answer: yes or no. And ask only your doctor; do not ask your physician's office staff, nurse, or physician's assistant or leave a request on voice mail.

Common responses from physicians include:

- *"I will help you,"* or *"I will be there for you when the time comes."* This may mean "I will refer you to hospice and palliative care," or "I will be sure you are kept comfortable, but I may not write a prescription for life-ending medication."
- *"Let's talk about that when the time comes,"* or *"Let's focus on treatment."* Seeking treatment from a physician who shares your values and is capable of telling you the bad news, as well as the good news, is important to ensure that you are referred to hospice at an appropriate time. Many patients want the comfort of knowing that the DWDA will be available to them if their condition deteriorates. For these patients, the *"we can talk later"* response is not acceptable.
- *"I don't know anything about Death With Dignity."* C&C's medical director can talk to your doctor physician-to-physician, provide her with a packet that includes all the necessary information, and answer questions. Give your physician our toll-free number, 877.222.2816, and assure him that C&C strictly protects confidentiality.
- *"My employer will not allow me to participate."* In some parts of Washington, such as Whatcom County, nearly all physicians work for a Catholic

healthcare provider that prohibits participation in the DWDA. Although the law permits providers to prohibit physicians from participating while on their employer's premises, nothing prevents a physician from participating off the premises. The law also prevents a provider from punishing a physician who does. Many physicians are unaware of these provisions of the law. Some, however, will not be comfortable participating under these circumstances.

- If your physician says "I don't believe in that," or "I'm against that," consider it a possible red flag. He may be less willing to provide you with adequate pain medication or provide an early hospice referral and may not practice patient-centered care.

Don't wait until it is too late to have this important conversation with your physician.

If your physician says that she will not support your choice, you should evaluate your relationship with that doctor. Will she make an effort to refer you to another physician who will? Has she provided you with excellent care? Do you have a long relationship with this physician?

Above all, you should never storm into your physician's office and demand assistance or approach him with a sense of entitlement. Although we have the legal right to aid in dying in Washington now, your physician is not required to participate and may have valid reasons for declining. The "Letter to my Physician" on the next page can help facilitate this conversation.

If your physician declines to participate, should you look for another one? For patients at a critical treatment juncture, changing physicians may not be the best option. It may be better to continue treatment and look for another physician who will support your choice to use the DWDA. We assist qualified patients with finding supportive physicians.

For general information about talking to your doctor about dying, please request the article, "Talking to Your Doctor About Dying," written by our Medical Director, Tom Preston, MD, or download it from the Resources page on our website.

If you have any questions about talking to your physician about Death With Dignity, call our office at 206.256.1636 or toll-free, 1.800.222.2816.

The following letter can be used to help facilitate a conversation with your physician about aid in dying and end-of-life choices. This document is not an advance directive.

Letter to My Physician Concerning My Beliefs About End-of-Life Care

Dear Dr. _____,

It is important to me to stay as healthy and active as possible and to have excellent and compassionate end-of-life care. My personal values and beliefs lead me to want treatment to alleviate suffering at the end of life. Most importantly, I want to ensure that, if I am terminally ill and if death is imminent, the experience can be peaceful for me and my family. If there are measures available that may extend my life, I would like to know their chance of success and their impact on the quality of my life. If I choose not to take those measures, I ask for your continued support.

If my medical condition becomes incurable and death the only predictable outcome, I would prefer not to suffer, but rather to die in a humane and dignified manner. I would like your reassurance that:

- If I am able to speak for myself, my wishes will be honored. If not, the requests from my healthcare representative and advance directives will be honored.
- You will make a referral to hospice as soon as I am eligible, if I request it.
- You will support me with all options for a gentle death, if I become terminally ill. This includes providing medications that I can self-administer, at the time of my choosing, to help me achieve a peaceful death. As you know, the State of Washington has enacted a Death With Dignity Law that authorizes physicians to prescribe medications to allow terminally ill patients to choose the time and manner of death.

I hope you will accept this statement as a fully considered decision and an expression of my deeply held views. I hope for your reassurance that you would support my personal end-of-life care choices as listed above. If you feel you would not be able to honor such requests, please let me know now, while I am able to make choices about my care based on that knowledge.

Signed: _____ Date: _____

Print Name: _____

For additional information and forms regarding end-of-life care and choices, please visit: www.compassionwa.org.

Client Support Volunteer Spotlight

Spokane

Roger Imes, originally from Wales, is “sort of retired,” and works in his wife’s health food store several days a week. Roger volunteered with Hospice of Spokane but felt that volunteering as a client support volunteer for C&C was a better fit for him due to his strong beliefs about patient-centered care. His goal is to support terminally ill patients as they make decisions about their death and to help identify supportive physicians and pharmacies. Working with C&C allows Roger to experience the profound connection that occurs when you are present during the dying process. Roger has a wonderful story about how he came to live in Spokane; a heartfelt kiss shared in Wisconsin in 1966 eventually led to moving from England to Spokane and then to marriage three years ago. **We are looking for an additional client support volunteer in Eastern Washington. If you live in this region, please consider volunteering.**



Vancouver



Jim Moody, PhD, is our only volunteer who provides client support in both Oregon and Washington. He has lived in the Washington city of Vancouver for 13 years and taught at Clark College. His retirement is a “fulfilling and busy, busy time.” He volunteers with the Kiwanis, Special Olympics, plays bluegrass guitar, and participates in a men’s group. It was a C&C presentation about Death With Dignity at the Kiwanis that rekindled Jim’s interest in supporting dying patients. Years ago, Jim taught about death and dying at a New Zealand medical school and volunteered with the Hemlock Society. Jim thinks the Oregon and Washington DWD laws can be very helpful, but many people do not know their rights and don’t get the help they need in making end-of-life choices. The biggest problem for the patients Jim has supported is finding doctors who are willing to participate. He encourages more people to volunteer to be client support volunteers, saying that “you see people at their very best, and there are wonderful examples of love and compassion,” and that “it rekindles your faith in humans.” **Jim is our only volunteer in Southwest Washington. If you live in this region, please consider volunteering.**

Seattle

Although **Joe Handelman** had a busy life with two young sons, a wife, and a business he created selling low-vision or impaired-vision equipment, he felt that his flexible schedule would still allow to him to volunteer for C&C. Joe’s interest in helping people at the end of life grew out of his experience with the death of his father who “was ready to die.” Although he became his father’s advocate, he was unable to get him into hospice in time. A friend of Joe’s who knew of his interest asked him if he had heard about C&C, and that led him to us. He says that volunteering has been gratifying. His first experience being present at a DWD “was a profound experience,” and Joe felt honored to be able to be of service. He sees his role as facilitating terminally ill patients’ wishes. Joe and his family enjoy living in Seattle, “a city that doesn’t require a car to enjoy the outdoors. The ability to walk to Puget Sound, the edge of the continent, is inspiring to me.”



A Call for Client Support Volunteers:

We need volunteers in Bellingham, Olympia, Centralia, Port Angeles, Sequim, and Eastern Washington. For information about volunteering, go to our website and click on “Get Involved.”

The Seattle Times

The Washington Voter-Approved Death With Dignity Act is Working

Published March 7, 2010

FOURTEEN years ago, my partner of eight years had a very bad death. Despite excellent medical and hospice care, his burning fevers, agitation and other symptoms remained intolerable. His suffering from the loss of all dignity and quality of life was even worse. Although he wanted to end his life when he became bedridden, it wasn't possible. His grueling, drawn-out dying process was demeaning, unnecessary and pointless.

Thanks to the compassion and wisdom of nearly 60 percent of Washington's voters in 2008, dying patients like my former partner now have the option to use the Washington Death With Dignity Act. The law gives qualified, terminally ill adults the right to ask their physicians for life-ending medication the patient may choose to self-administer to bring about a peaceful, humane death. The law also gives medical providers the right not to participate.

The Washington Department of Health recently released its first annual report on the new law. Just as we predicted during the Initiative 1000 campaign, only a very small percentage, less than 1/10 of 1 percent of terminally ill Washingtonians elected to take life-ending medication under the law. Most were suffering from end-stage cancer and were receiving hospice care at the time of death.

Several of those who received life-ending medication died without taking it. All of these patients, whether they took the medication or not, gained peace of mind and comfort from knowing that if their suffering became unbearable, they had a way out.

The act's benefits extend well beyond the terminally ill patients who want to use the law. In Oregon, the law spurred conversation, education and improvements in end-of-life care across the board.

Researchers have also concluded that there is no evidence of harm to the elderly, the uninsured, the poor or the disabled. Forbes Magazine recently ranked Oregon second among states as a good place to die, while Washington ranked 18th. We expect improvement in Washington as the law prompts education, conversation and better end-of-life care.

Anti-choice activists will use the occasion of the Health Department's annual report to make the same fabricated,

undocumented claims they made during the campaign. They will excoriate the report and the process. But take their statements with a grain of salt. The real, rarely acknowledged reason for their opposition to the law is, and always will be, moral judgment.

Don't be fooled by their supposed "concern" for the dying. These are the same people who believe that patients in a persistent vegetative state should be kept alive by medically administered artificial nutrition and hydration, even when it is contrary to the patient's legally documented wishes and the wishes of their families.

Opponents will also repeat that hospice and palliative (comfort) care can manage any and all suffering, making Death With Dignity unnecessary. Compassion & Choices of Washington believes that hospice and palliative care are essential components of excellent end-of-life care, but some suffering is beyond their ability to relieve.

The American Academy of Hospice and Palliative Medicine agrees, stating, "Excellent medical care, including state-of-the-art palliative care, can control most symptoms and augment patients' psychosocial and spiritual resources to relieve most suffering near the end of life. On occasion, however, severe suffering persists ... "

No one should have to die the way my partner did. Thanks to the Death With Dignity law, mentally competent, terminally ill patients now have another end-of-life option. The annual report indicates the new law is working just as it was designed to work. Death With Dignity in Washington has been legal, safe and rare.

Robb Miller has been the executive director of Compassion & Choices of Washington since 2000 and was one of the leaders of the Initiative 1000 campaign, which legalized death with dignity in Washington in 2008.



Thank you Zeeks Pizza!

for providing free pizza and salad at our monthly volunteer meeting. Zeeks has provided generous in-kind support to C&C for more than 10 years. Please patronize their restaurants: www.zeekspizza.com or 206-285-TOGO.

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2010 Legislative Session Update from C&C Lobbyist, Kate White Tudor, Esq.

Budget: Due to a \$2.6 billion shortfall Gov. Gregoire proposed an all-cuts budget (required under state law) that would have eliminated many critical programs, including the hospice program under Medicaid. Thanks to the advocacy efforts of C&C and other allies of the Washington State Hospice and Palliative Care Association, we managed to preserve the hospice benefit in the house and senate budgets. Since the Legislature is still in special session as we go to press, we cannot be certain about the outcome of the revenue or budget negotiations.

Pain Management: Rep. Jim Moeller (D-Vancouver) spurred a vigorous discussion of pain management policies when he introduced HB 2391, which would have required continuing education in pain management for all healthcare professionals able to prescribe addictive medication, but this bill never came up for a vote. Stakeholders worked with Rep. Moeller to pass a different measure to address the increasing problem of addiction and patient overdose on prescription medications. HB 2876 directs the Department of Health to issue new rules for prescribing pain medication, including dosage guidelines, prescription tracking, and recommendations for pain specialist consultation. We successfully lobbied for a broad exemption for patients at the end of life, and

we will monitor the rule-making process to ensure this law does not make it more difficult for dying patients to get appropriate palliative care.



Rep. Dawn Morrell

Secure Medicine Return: This program, which would have allowed citizens to safely dispose of dangerous medications, was closer than ever to passing this year. The proposed legislation would require pharmaceutical companies to pay for the disposal program, just like computer manufacturers now pay to dispose of electronic waste. Unfortunately, pharmaceutical companies fought hard against the bill, even

though it was estimated to cost less than \$1 million for the entire state (less than a penny per prescription sold). Sponsor Rep. Dawn Morrell (D- Puyallup) plans to try again next year, when we hope Washington adopts this sensible program. To learn more about the legislation or to find an existing disposal program, visit www.medicinereturn.com.