



## Hospital "Alliances" Threaten Patient Choice

Recently, a wave of takeovers – euphemistically called alliances – between Catholic and secular hospitals threatens to erode access to choice at the end of life in Washington.

In early 2011 Southwest Medical Center in Vancouver, Washington, and its affiliated hospice came under the control of PeaceHealth, a large Catholic health care system that operates under the Catholic Ethical and Religious Directives for Health Care Services. These directives prohibit physicians and pharmacists employed by Catholic providers from participating in



United General Hospital in Skagit County is planning to lease the hospital to PeaceHealth, a Catholic health care system.

the Death With Dignity Act while on their employers' premises. At Southwest the prohibition on employed physicians has also had a chilling effect on physicians not employed by Southwest who have hospital privileges.

While many Catholic-affiliated providers do provide excellent medical and hospice care, most have also adopted policies that prohibit their staff from providing information, support,

and even referrals related to the option of Death With Dignity (DWD). (continued on page 7)

## Funding for Death With Dignity Act Annual Reporting Preserved!

An amazing thing happened in Olympia last month. In a legislative hearing room, representatives of Compassion & Choices of Washington (C&C) and the Washington State Catholic Conference sat down before a budget committee. Together they successfully advocated for the restoration of funding to produce the Death With Dignity Act's (DWDA) annual report.

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STATE OF WASHINGTON  
DEPARTMENT OF HEALTH

## DOH Upholds the Right of Hospice Staff to Discuss Death With Dignity

Thanks to our advocacy, the right of hospice employees to provide basic information about the Death With Dignity Act (DWDA) to their patients has been established.

In a letter dated November 5, 2011, Steven M. Saxe, the Director of the Washington Department of Health's Office of Health Professions and Facilities wrote: "Regardless of whether or not a given hospice agency chooses to participate and promote the DWDA, health care providers who are employees of hospice agencies have the protected right to offer basic information regarding the DWDA to their hospice patients."

As a result of Director Saxe's letter and the DSHS "Dear Administrator" letter, we are increasing the pressure on medical and long-term care providers who place their religious beliefs or organizational

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Last November, the movement for choice at the end of life lost one of its champions. Dr. William O. Robertson, who was known as "Robbie" by most of his peers, was a member of our board of directors for seven years. He was also the president of the board from 2001 to 2004. So I had the privilege of working closely with him for many years.

A complete list of Robbie's life accomplishments, accolades, and awards would be far too long to print here, but here is the short list: Professor, Professor Emeritus, Chair of the Department of Pediatrics, Associate Dean and Medical Director of the University of Washington Medical School (where he won the medical school's distinguished teaching award so often that he was finally named "Teacher Superior in Perpetuity," an award that took him out of competition once and for all so that other professors had a chance); attending physician at UW Hospital, Harborview Hospital, and Children's Hospital, where he also served as Medical Director; Medical Director of the Washington Poison Center, known for his introduction of the "Mr. Yuk" symbol to the Northwest; and President of the King County Medical Society and the Washington State Medical Association (WSMA).

Robbie was an advocate for patient safety before "patient safety" existed. For example, his crusade against physician "scribbling" led to a 2006 law that mandated legibility for all medical prescriptions to reduce error. He also successfully lobbied to have all solid medications individually imprinted with identifying information in the state of Washington, which led to the FDA making this a national requirement.

The quality that I admired most about Robbie was that when it came to his profession, he lived in a fact-based world; he made decisions and choices based on science and research – not dogma, the expectations of others, or tradition. He was also a skeptical, intellectually curious man who questioned orthodoxy.

In the late 90s, when he joined our board of directors, many of his peers and the leadership of the WSMA were vehemently opposed to the mission of Compassion & Choices of Washington. So it took real courage for Robbie to join our board, and I know he took some heat for it. But, in true Robbie fashion, when his peers argued that legalizing aid in dying would create a slippery slope, he replied: "I haven't seen any studies or research that support your position."

As you can imagine, the addition of a past president of the state medical association to our board of directors was a big deal.

Now we know that Robbie was not only right, but ahead of his time.  
(continued on page 6)



Dr. William O. Robertson  
Nov. 24, 1925 - Nov. 30, 2011

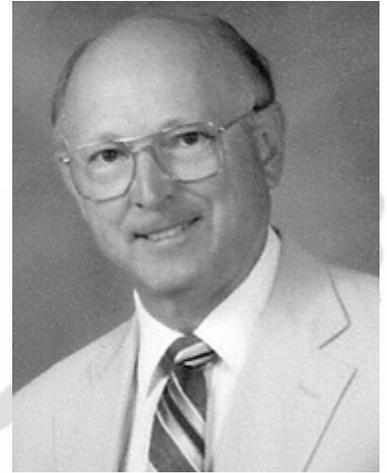
# In Memoriam: Neil Thorlakson, MD, 1926 - 2012

In 1990 Neil Thorlakson, MD, was the Chair of Physicians for Initiative 119 and became a powerful speaker in support of legalizing physician aid in dying. He had retired from a long, distinguished career as an ophthalmologist and worked tirelessly in support of I-119 which did not pass in 1991.

I-119 was the very first time that physician aid in dying was on the ballot in the United States, and public opinion was very polarized at that time. Neil's courage in taking a public position resulted in his being attacked by his colleagues and receiving hate mail. He was also the target of some of the opposition advertisements which claimed – erroneously – that there were no safeguards. One ad claimed that “Even your eye doctor could kill you!”

Many people are unaware that the I-119 Campaign paved the way for the passage of Measure 16, the Oregon Death With Dignity Act, in 1994, which – in turn – paved the way for the passage of I-1000 here in Washington in 2008. Therefore Neil's efforts in 1991 ultimately made it possible for him to self-administer life-ending medication early this year to end his suffering from pancreatic cancer, with client support from C&C.

Compassion & Choices of Washington mourns the loss of this outstanding leader in the movement for choice at the end of life.



## Rabbi Anson Laytner Joins Advisory Committee



We are very pleased to announce that Rabbi Anson Laytner has joined our advisory committee. He currently is a grant-writer for the Jewish Family Service of Seattle and an adjunct professor with Seattle University's Department of Theology and Religious Studies. Anson holds a Masters of Hebrew Letters and rabbinic ordination from Hebrew Union in Cincinnati, a Masters in Not-for-Profit Leadership from Seattle University, and an honorary Doctorate in Divinity from Hebrew Union College.

He has a long history of community service and has served as a chaplain with Kline Galland Hospice, the interim rabbi at Congregation Kol HaNeshamah in West Seattle, and executive director of the Seattle Chapter of the American Jewish Committee. For 11 years, during the peak of the AIDS crisis, he was also the executive director of Multifaith Works, a Seattle nonprofit agency serving people with AIDS or other life-threatening illnesses.

Anson was married to the late Merrily McManus Laytner, who died of cancer in 2011. Between them, they shared three daughters, three sons-in-law, and four grandchildren.

He is the author of two books and over sixty articles on subjects ranging from Jewish theology to the Arab-Israel conflict to the Chinese Jews. His goal in his in-progress work, *Letting Go of God*, is to study god-concepts and the meaning of suffering.

When asked why he chose to volunteer for C&C, he said: “When Merrily was dying, she enrolled in a hospice program, but she also acquired Death With Dignity medication. Although she elected not to use it, just having the medication gave her the sense of control she desired. Having lived through my wife's experience and also witnessing the dying of so many other people, I wanted to transform their suffering into something positive. If I can help relieve some of the anxiety around dying; if I can reassure dying people (and their loved ones) that by choosing Death With Dignity they are choosing well, then I will have done this.”

# Surgery and Advance Directives

Most surgery-bound patients thoughtfully review their advance directives for health care before a scheduled procedure and are confused when they are presented with a waiver that temporarily revokes their advance directives while under the care of the surgical center.

For example, one surgical center's admittance disclosure states that "Prior to sedation, the Pre-Op Nurse shall question patients to determine if they have an Advance Directive with them for the scheduled procedure. If so, the patient shall then be notified that we do not honor advance directives or DNR (do not resuscitate) during the time the patient is in our facility."

We discussed this conundrum with Dr. Joe Jack Davis, a C&C client support volunteer and retired surgeon from Harrison Medical Center in Bremerton. Dr. Davis explained that surgery and anesthesia are invasive technologies with low, but definite, risks for a life-threatening event.

To ask a surgeon and anesthesiologist to abandon their craft and allow a patient to die on the operating table places an unreasonable burden on them. Surgeons do not offer surgery to patients who they believe will not survive the surgery, and many will not agree to perform a surgery without the ability to try to bring the patient through it alive.

The patient must consider the pros and cons of the surgery. If there is a high likelihood that the surgery would help to recover quality of life, perhaps you should have the surgery and temporarily waive the advance directive. If the surgery is not likely to provide lasting quality of life, and not being resuscitated or revived is important to you, perhaps you should consider opting out of the surgery.

If you do agree to surgery, surgeons generally claim the right to keep you alive artificially if your systems start to shut down during the procedure. Therefore, you will be intubated or receive other life-sustaining therapies regardless of your wishes to the contrary – thus the advance notice of this at the time of consent for surgery.

Having surgery, however, doesn't mean your advance directives won't inevitably be honored. Ideally, the decision-maker you have appointed will be informed about your condition and then act on your behalf to start making decisions post-operatively. But the time frame when this is allowed may not be clear. Most people are unaware that there is a time period after surgery in which a death is considered a result of the surgery, and therefore goes into that surgeon's mortality statistics. This can be a factor in how long a patient receives unwanted life-sustaining treatment.

C&C recommends that all patients have a "what if" conversation with their surgeons prior to surgery. Ask what would happen if you had a stroke during your procedure and intubation was necessary to preserve your life. Ask how long you might be intubated and when your health care agent or other legal surrogate decision-maker would be able to discontinue that or other life-sustaining treatments as stated in your advance directives.

Finally, prior to surgery, review your advance directives; make sure the hospital, your family, and your health care agent have copies; and notify your family and health care agent that you will be having surgery.

For questions about this issue or advance directives, please contact our office.

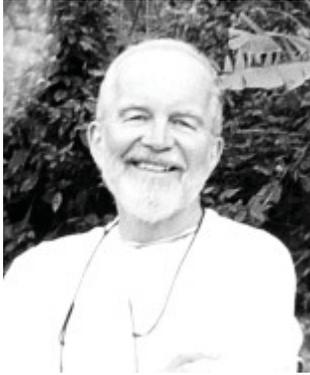
***"...the patient shall then be notified that we do not honor advance directives or DNR..."***

## Are you a good listener? Become a Client Support Volunteer!

Client Support Volunteers are currently needed in all parts of Washington except Seattle/King County. If you are looking for a fulfilling volunteer opportunity, contact us today. For more information, visit our website [www.compassionwa.org](http://www.compassionwa.org), and click on "Get Involved."

# Introducing Our New Client Support Volunteers

Bremerton



**Joe Jack Davis, MD**, is a recently retired physician and general surgeon who practiced at Harrison Medical Center for 33 years.

Dr. Davis and his wife lost a child to cancer long before the subject of a good death was discussed. He is also a cancer survivor.

When asked about his motivation for volunteering for C&C, he replied, "During a long career of taking care of acutely and chronically ill patients, I saw way too many people die poorly when dying did not have to happen that way. Gradually it became clear to me that usually bad deaths were attributable to poor planning on the part of the dying patient. Now I realize that poor deaths are due to a combination of factors that includes patients, doctors, and families – none of whom are communicating well with each other."

Dr. Davis says that C&C had been on his radar for a long time. "When I realized I could volunteer, I knew my background would help me empower people to have a good death. That is what I hope to accomplish."

Vancouver

**Ashley Phillips** is a recent college graduate who reports that she is "back at it again," training to become a paramedic. She is also an intrepid traveler. On Christmas Eve every year she chooses a part of the world she's never been to and buys a plane ticket to explore that area the following March.

When asked why she chose to volunteer for C&C, Ashley said, "I've been watching documentaries about this issue for years, but I just recently made the decision to become actively involved. That led to calling the office to find out how I could help. I cannot stand by while people are in distress, and I'm an avid fighter when it comes to human rights. I see volunteering as an opportunity to help in both of these areas."

Ashley reports that it's been an amazing experience so far. "The staff, volunteers, and clients have been nothing short of incredible. I'm looking forward to a fulfilling, rewarding experience volunteering for C&C."



## Two Ways to Give to C&C Without Spending a Dime!



Would you like to help C&C, but feel you're unable to contribute? Here are two great ways to give without spending a dime:

1. Ask friends and family to make a contribution to C&C in your honor in lieu of birthday or other gifts. How many of us really need more stuff? Just be sure to tell them to use the C&C Seattle address below.
2. Arrange for a memorial request (a statement in your obituary) asking that donations be sent to Compassion & Choices of Washington, PO Box 61369, Seattle, WA 98141. When you arrange for a memorial request to C&C, it enables your values and commitments to carry on in the service of others.

# Research Roundup



A newly published study was designed to assess whether the treatments provided were consistent with what was documented on the Physicians Orders for Life Sustaining Treatment (POLST) form. The study found **that POLST orders about resuscitation were honored 98 percent of the time, and orders to limit medical interventions were honored 91 percent of the time.** "This latest research builds upon our previous findings that suggest **the POLST program offers significant advantages over traditional methods like advance directives and Do Not Resuscitate orders to communicate patients' preferences about life-sustaining treatments,**" said lead author, Susan Hickman, Ph.D., Associate Professor in the Schools of Nursing at Indiana University and Oregon Health & Science University. (Journal of the American Geriatrics Society, Volume 59, Issue 11, pages 2091–2099, November 2011.)

A recent report by the AARP Public Policy Institute and the American Bar Association's Commission on Law and Aging states that **"Physician Orders for Life-Sustaining Treatment (POLST) is a promising program to elicit and honor the treatment goals of people with advanced progressive illness or frailty. Research shows that POLST effectively communicates patient treatment choices, whatever they may be, without sacrificing comfort care."** The report documents the evolution of POLST in 12 states and highlights lessons learned for states developing and implementing new programs. (<http://alturl.com/cc73p>.)

## Robb Report (continued from page 2)

Fifteen years of legal aid in dying in Oregon and three years here in Washington have proven that Death With Dignity is safe, rare, and a great source of comfort to terminally ill patients. And, just as he said, there is no evidence of any slippery slope.

I'm glad Robbie lived to see Initiative 1000 pass in 2008 with nearly 60 percent of the vote and in all but nine counties in Washington. And I'm sure he smiled when the Seattle Times published a story reporting that the WSMA's own poll indicated that 50 percent of its members supported the passage of I-1000.

I feel very privileged to have known and worked with Robbie. All of us at Compassion & Choices of Washington – the members of our board of directors and many volunteers past and present – will be forever grateful to him for his leadership and commitment to the social justice cause of patient-centered end-of-life care and choice at the end of life.

## About POLST

**What it is:** A medical order describing end-of-life treatment preferences.

**Who it's for:** People with life-limiting illnesses or advanced frailty.

**Available in:** Oregon, Washington, and 10 other states, with programs developing in 22 more states.

**Filling it out:** Tell your doctor about your goals of care and ask whether POLST is right for you. You and a qualified health professional must complete and sign the form.

**Where to get it:** Contact our office. We provide POLST forms at no charge.

**More info:** <http://www.wsma.org/patients/polst.html>



Alberta Golden, MLS, and Senior Medical Director Tom Preston, MD. Alberta recently stepped down from C&C's board of directors after serving ten years. She continues to teach advance directive classes for C&C.

# Hospital "Alliances" (continued from page 1)

The ensuing conversion of Southwest Hospice from a patient-centered hospice provider with good policies on DWD to one with unsupportive, provider-centered policies was a significant setback for the community, where nearly 60 percent of the voters in the surrounding area supported the passage of Initiative 1000.

Now two more alliances have been announced: one between PeaceHealth and United General Hospital (UGH) in Skagit County, and another between Swedish and Providence in Seattle and Western Washington.

UGH is in a small public hospital district, meaning that it is owned, governed, and supported by local citizens. So if the hospital board's plan to lease the facility to PeaceHealth is realized, physicians and other medical staff at a public, tax-supported hospital will be required to adhere to the Catholic directives. But as a practical matter, UGH employs only a few physicians, and the impact on the community should be minimal.

Most importantly, the local hospice co-owned by UGH – Hospice of the Northwest, which has excellent, patient-centered DWD policies – will not be affected.

Each of these alliances resulted in the creation of a patients' rights coalition with representatives from C&C; reproductive rights groups; and at UGH, an organization representing parents of gays and lesbians (PFLAG). Although unable to prevent these alliances

from occurring, our coalition representatives were able to meet with hospital CEOs and PeaceHealth representatives to mitigate some of the negative impacts.

Fortunately, the Swedish/Providence alliance appears to be a true alliance. At our meeting with Swedish representatives in October, we were assured that a new governance structure would be created to protect and preserve Swedish's secular identity, and that Swedish and its hospice would not operate under the Catholic health care directives.

Following up on our meeting, Dan Dixon, Swedish's Vice President of External Affairs, wrote: *"We understand your concerns about the potential impact to Swedish's current policies regarding hospice care and physician autonomy. We want to reiterate that Swedish's policies will not change with regards to aid in dying issues, and our current plan is to retain Swedish's hospice program separate from Providence's program. Honoring the physician-patient relationship and assuring that patients are able to receive all information relevant to their condition are important values to Swedish, and that will not change."*

Although we would have preferred that Swedish ally with an organization that honors all patients' end-of-life choices, we appreciate Swedish's efforts to preserve its existing policies on aid in dying. And we will be watching carefully to ensure they keep their promise.



Derek Humphry, founder of the Hemlock Society, and Midge Levy, one of the founders of the Hemlock Society of Washington State and current Vice President of C&C.



## On the Lighter Side

"I think the most unfair thing about life is the way it ends. I mean, life is tough. It takes up a lot of your time. What do you get at the end of it? A death! What's that, a bonus? I think the life cycle is all backwards. You

should die first, get it out of the way. Then you live in an old age home. You get kicked out when you're too young, you get a gold watch, you go to work. You work for forty years until you're young enough to enjoy your retirement! You go to college, you do drugs, alcohol, you party, you have sex, you get ready for high school. You go to grade school, you become a kid, you play, you have no responsibilities, you become a little baby, you go back into the womb, you spend your last nine months floating.... You finish off as a gleam in somebody's eye."

~Sean Morey, Comedian



## Volunteer Spotlight: Louise Hull, MA

Louise Hull, MA, a sociology professor at Green River Community College, has been a C&C client support volunteer for nearly five years.

Louise became acquainted with C&C when she invited Robb Miller, C&C's Executive Director, to speak to her Sociology of Death and Dying class about the issue of physician aid in dying.

When asked why she chose to volunteer for C&C, Louise said: "I have cared for, and lost, several close family members and know firsthand that knowledge of end-of-life choices can have a positive effect on the dying person and their family."

Last fall, Louise helped curate a critically acclaimed exhibit on Victorian funeral practices which included her presentation titled, "A Death-Denying Culture: Thinking Outside the Pine Box." This presentation describes how various cultural factors feed death-denial, which then leaves us unprepared for inevitable losses. She is currently working on a book about her experiences as a C&C client support volunteer.

Thank you for your dedicated service to our clients and for your commitment to choice at the end of life, Louise!

## DOH Upholds Right of Hospice Staff (continued from page 1)

policies ahead of their patients' and residents' rights to understand all their legal end-of-life options and make informed decisions. The DSHS letter instructed administrators of long-term care facilities to notify residents about their DWD policies and affirmed residents' rights to receive information about the DWDA.

Nearly three years after the enactment of the DWDA, several mostly Catholic-affiliated hospice providers still maintain unconscionable, unethical policies prohibiting their staff from discussing DWD, or even referring their patients elsewhere for information.

Our advocacy efforts like these and others we have in the pipeline will not end until medical and long-term care providers practice patient-centered care and comply with state and federal regulations that protect patients' access to information.

If you or a member of your family were denied information about the DWDA by a medical, hospice, or long-term care provider, please contact our office.

### Quote of Note

*"The truth is...that patient-centered care demands that the ways in which a person is cared for ought always to be under his or her control. The patient is the boss; we are the servants. They, not others, should direct their own care, and the doctors, nurses, and hospitals should know and honor what the patient wants."*

~ Don Berwick, former administrator of the Centers for Medicare and Medicaid Services, speaking at the Institute for Health Care Improvement Forum in December 2011.

## Coming Soon: New Advance Directive for People With Alzheimer's Disease or Dementia

C&C has teamed up with Seattle University Clinical Law Professor Lisa Brodoff to create a new advance directive for people with Alzheimer's disease or dementia.

Professor Brodoff was instrumental in the passage of legislation in Washington State creating the Mental Health Advance Directive, for people with mental illness. Washington's statute is considered model legislation for states seeking to expand the rights and planning options for people with mental illness.

The new Alzheimer's/Dementia Advance Directive will be based on one created by Professor Brodoff for a 2009 Elder Law Journal article titled *Planning for Alzheimer's Disease with Mental Health Advance Directives*. It will be available free of charge by downloading from our website or via regular mail.

The new Alzheimer's/Dementia advance directive is not designed to replace existing advance directives (Living Will, Durable Power of Attorney for Health Care), but will work in concert with these documents to ensure that patients' wishes related to issues not addressed in standard advance directives are documented and honored, when possible.

These issues include preferences regarding care in and outside of the home, financing of care, suspension of driving privileges, and even issues such as preferences regarding future intimate relationships.

At this time, we cannot predict when the new Alzheimer's/Dementia Advance Directive will be available. If you would like to receive a copy as soon as it becomes available, please contact our office at 206.256.1636, 877.222.2816 toll-free, or [info@CompassionWA.org](mailto:info@CompassionWA.org), and request to be added to the waiting list. We will then email or mail you the new directive as soon as it becomes available.



Lisa Brodoff,  
Associate Professor, Seattle  
University School of Law

## DWDA Funding Preserved (continued from page 1)

On what issue do the Catholic Conference and C&C agree? We both want the accountability that reports by the Department of Health provide. On an annual basis, these reports show the DWDA is working as voters intended, and vulnerable people are protected from abuse.

At 11 a.m. on Monday, December 12, our lobbyist, Kate White Tudor, learned that DWDA reporting funds were targeted for elimination. She testified in favor of restored funding that afternoon. To watch the hearing: <http://alturl.com/7vm57> (testimony by the Catholic Conference starts at 43:41, by C&C immediately after).

Thanks to an amendment offered by Rep. Reuven Carlyle (with support of Reps. Eileen Cody and Ross Hunter), the House Ways & Means Committee amended the budget bill to restore funds for DWDA reporting. The amendment was retained as part of the bill when it passed the House floor Tuesday evening, and a similar amendment process restored funding on the Senate side.

As the steward of the DWDA, we continually advocate for its impeccable implementation. The state's annual report is an important tool to ensure the practice has no unintended consequences – and on that, we and the Catholic Conference can agree.



Derek Humphry, founder of the Hemlock Society,  
presenting to a full house at C&C's 2011 Annual Meeting.

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## Robb Miller to Present at Bellingham Unitarian Fellowship on Feb. 19

C&C's executive director, Robb Miller, will be giving sermons called "The Lessons of Compassion" at the 9:15 and 11:15 a.m. services on February 19 at the Bellingham Unitarian Fellowship (BUF), located at 1207 Ellsworth Street, Bellingham, 98225. The community is welcome and encouraged to attend.

As part of its monthly Social Justice Program, the BUF has generously agreed to donate collections from both services to C&C. For more information and directions to the BUF, go to <http://www.buf.org> or call 360.733.3837.

During the Grand Hour with coffee and conversation between services, there will be a C&C display table staffed by our Bellingham-area client support volunteer, Cynthia Heft.



At 1 p.m. Robb will lead a workshop about advance planning and guide participants through the advance planning process. Class members will leave with a completed, notarized C&C Advance Directive which combines a Living Will and a Durable Power

of Attorney for Health Care into one document. There is no cost for the class, documents, or notarization.

If you are an adult living in the Bellingham area who hasn't made advance directives, you will never have a better opportunity to complete these essential documents. To register for the workshop, contact the BUF at 360.733.3837 or [admin@buf.org](mailto:admin@buf.org).