U.S. Bishops Attack Patient Autonomy

In June the United States Conference of Catholic Bishops (USCCB) met in Washington to formalize their opposition to patient autonomy at the end of life and adopted a policy statement condemning what they refer to as “assisted suicide.”

The bishops’ vote – the first in the USCCB’s history – signals a campaign of increased intensity to undermine public support for end-of-life choice and chastise and shame those who seek legal reform.

Riddled with inaccuracies and debunked arguments against aid in dying, the statement takes direct aim at Compassion & Choices (C&C), pointedly co-opting our use of the words “compassion” and “choices,” asserting that they hold these values while we do not.

As made clear in their five-page statement, their reasoning has no consideration for the rational, thoughtful decisions of terminally ill adults seeking solace in their final stages of suffering.

Oblivious to the peace of mind and comfort provided by aid in dying and volumes of peer-reviewed medical research proving that aid in dying is safe, they accuse us of devaluing life, preying on the vulnerable, and abetting elder abuse.

As soon as we learned about the scheduled vote, we organized a press conference at the same hotel where the bishops were meeting. Powerful statements were made by C&C National’s president, a Washington physician with ALS, a Catholic widower of a patient who used the Washington Death With Dignity Act, a Methodist minister, and our medical director in support of the choice of aid in dying.

While we believe the bishops have every right to their opinions and to issue religious guidance to the faithful, their determination to undermine end-of-life choice for everyone indicates they are increasingly out of touch with the vast majority of Americans. People of every faith and belief – including Roman Catholics – believe in permitting terminally ill patients to make their own choices about the final days of a terminal disease.

For many years, the Catholic hierarchy actively hid its anti-choice activism using proxies such as disability-rights groups to further its agenda. C&C welcomes – in fact we are deeply (continued on page 9)

Long-Term Care Administrators Educated about Rights at the End of Life

Thanks to our advocacy, the Washington Department of Social and Health Services (DSHS) issued an important letter to administrators of long-term-care facilities throughout Washington. Many of these facilities have adopted policies prohibiting their staff from discussing Death With Dignity (DWD) with patients, or even referring their patients elsewhere for information. The letter from DSHS instructs facilities to notify residents about their DWD policies and reaffirms the rights of long-term-care residents to receive information about DWD. This letter states: “Regardless of policy, the nursing home/facility should provide residents, and those providing support to residents, access to information about the [DWD] Act and other related information as requested.”
Our newest staff member is Phoenix Ivan Aquino, born on April 12 of this year. Phoenix is the son of Amber Wade, MSW, our director of client support, and her life partner, Eddie Aquino. With such bright, devoted parents, I’m sure Phoenix has a great future ahead of him.

Phoenix’s job description is to eat, sleep, soil his diapers, occasionally cry, and endlessly entertain all adults within a two-mile radius. Among his duties, he seems to have a particular talent for sleeping.

Not surprisingly, having a newborn around got me wondering what things will be like when he’s older. It’s quite feasible that he could live to the age of 90, which would take him into the next century.

By the year 2100, I have no doubt that the choice of a dignified death will be legal throughout the United States. But it won’t be made legal via legislation, legal challenges, or initiative campaigns. It will be legal because the standard of medical care will have evolved enough to acknowledge that suffering is defined by the patient, not the medical providers. Aid in dying will be a form of palliative care.

Currently, the option of palliative sedation (sedation to unconsciousness for the rest of one’s life) is available only to patients whose pain and symptoms cannot be managed by any other means. But initiating palliative sedation is the purview of medical providers, not patients.

There is no consensus among hospice and palliative care providers that nonphysical or “existential” suffering warrants palliative sedation for terminally ill patients. So, at this time, dying patients who suffer unbearable “existential” suffering such as a total loss of all quality of life are not eligible for palliative sedation. If these patients are fortunate enough to live in Montana, Oregon, or Washington, they have the option of Death With Dignity. But elsewhere, they must depend on the largess of their medical providers or take matters into their own hands.

By 2100, I believe there will be a better, more accurate understanding of suffering at the end of life, one that encompasses existential suffering. And when dying patients’ suffering becomes unbearable, a peaceful death via palliative sedation and aid in dying will be options.

Antichoice extremists will no doubt begin calling palliative sedation “euthanasia,” just as they currently describe aid in dying as “assisted suicide.” But because palliative sedation will be provided to treat unmanageable suffering and not to hasten death, their arguments will have no traction, just as their baseless arguments against aid in dying have been dismissed in recent years.

By the time Phoenix approaches his final days, I believe he will have no fear of the dying process. The right to a humane, peaceful death will be no more controversial than our right to decline medical treatment is now.
Five Ways You Can Support Our Death With Dignity Law

Our devoted, longtime client support volunteer and generous supporter, Frans Wery, died on April 17, 2011. Frans grew up in Holland where he completed medical school. He then moved to the United States and served for two years as a Navy physician. Eventually he joined Group Health Cooperative where he worked for 29 years in family practice and emergency medicine. His work-related end-of-life experiences and issues raised by the Initiative 119 campaign inspired Frans to become more involved, and that led him to Compassion & Choices of Washington.

Frans was a tall, strapping, good-natured man who will be remembered for his wonderful sense of humor and a heart full of compassion. During the 11 years he volunteered, Frans empowered dozens of our clients and their families through the dying process, ensuring they were able to have peaceful deaths on their own terms. He also mentored many new client support volunteers. He will be dearly missed.

Remembering Frans Wery, MD

July 31, 1926 - April 17, 2011

Announcing the Winners of our 2011 Student Essay Contest

Thanks to a generous gift earmarked for the purpose of underwriting an essay contest, we were able to raise the consciousness of many young people about this important issue.

Our first prize winner, Megan K. Brennan, 18, from Shelton won $1,000 for her essay titled “Thinking About Death Is Just For Old People, Right?” Megan wrote about her grandfather who used the Death With Dignity Act, and her great-grandmother who did not, writing: "Within our family, the restrained silence of choices surrounding death has been shattered. Even the ‘middle agers’ are thinking out loud. All are feeling very positive about hospice and the Washington and Oregon progressive Acts."

The second prize was awarded to David Kennedy, 18, from Gig Harbor who wrote an essay opposed to Death With Dignity called “Where There is Life, There is Hope.” While we do not agree with his conclusions, his essay was well written and researched: “Giving people the option of self-medicating the end may alleviate some suffering, but it also precludes the possibility of a miracle… If living well, living with purpose, and living intentionally make us human, will giving people the option to die intentionally make a positive impact in our world?” David won $500 for his effort.

Third prize winner, Christopher Stenson, 16, from Bothell won $250 for his essay titled “Impact of the Washington State Death With Dignity Act.” Christopher writes: “The ability to take charge of one’s life is the key driving force behind proponents of the law, as it offers something that many people faced with terminal conditions gradually lose – control.”

Five honorable mentions and $50 prizes were awarded to Madison Birdsall, 17, Maple Valley; Brennan Payne, 18, Port Orchard; Linsey Theda, 17, Redmond; Alisa Vangrunst, 16, Sammamish; and Ryan Wigley, 18, Pacific.

To read all the prizewinning essays, go to our website, www.CompassionWA.org, and click on Essay Contest.
Welcome Carol Gipson

We are pleased to announce that Carol Gipson, MA, is our new Director of Development. Carol’s hiring was made possible by a few generous donors and ongoing support from the Riverstyx Foundation.

Prior to joining C&C, Carol was a fundraiser and grant writer at United Way of King County. From 2002 to 2010, she lived in Switzerland, where she launched two businesses. Prior to that, she was the executive director for a statewide low-income housing agency. Carol’s first career was as a psychotherapist in San Francisco, California, where she specialized in treating children and adults for grief and trauma.

“I’m delighted and honored to join the dedicated team at C&C,” states Carol. “My goal is to be an effective steward of the resources contributed by our many supporters. As a C&C supporter, you can take pride and inspiration in the recent accomplishments described in this newsletter. It’s a great privilege for me to be part of an agency that helps people facing difficult end-of-life decisions.”

Long-Time Client Support Volunteer Gretchen DeRoche Joins C&C Board

Gretchen DeRoche has a long history of community service to those facing the end of life. As a group leader at the Seattle AIDS Support Group (now the Seattle Area Support Groups), she brought into her home several people who were dying from complications of AIDS and had no place else to go. When the AIDS crisis abated in 1997, Gretchen added volunteering for C&C to her schedule. She is now one of C&C’s longest-serving client support volunteers. In 1992 she received the Jefferson Award, a national award honoring community and public service.

In 2008, Gretchen stepped into the role of client support team coordinator, essentially an unpaid part-time job screening, training, mentoring new volunteers, assigning clients, and much, much more.

In the course of nearly 15 years of volunteering for C&C, Gretchen has donated countless hours and assisted hundreds of individuals.

New Law Creates Designated Agent for Funeral Arrangements

Thanks to the efforts of Rep. Steve Kirby (Democrat, Tacoma), the People’s Memorial Association (PMA), and other advocacy groups, Washington residents will now be able to name a designated agent for funeral arrangements. The law passed during the 2011 legislative session and took effect on July 22.

The two other ways to ensure control over the disposition of your remains are to sign and have witnessed a document expressing your wishes (called a Disposition Authorization), and prepay or prearrange your funeral.

For a Disposition Authorization, contact our office. For information about prearranging low-cost cremation or burial, C&C highly recommends PMA (www.peoplesmemorial.org or 866.325.0489 toll-free).

C&C Advance Directive Updated and Improved

C&C’s highly regarded advance directive, which combines a living will and durable power of attorney for health care into one document, has been improved and updated.

These include new sections allowing you to name a primary and alternate designated agent for funeral arrangements and ensuring that your wishes will still be honored if you are admitted to a religiously affiliated health care institution.

As usual, our advance directive is free; download it from our website or email or call our office. Note: There is no need to redo your current C&C advance directive unless your wishes have changed.
Death With Dignity Attacked

We are pleased to report that Senate Bill 5378, attacking our state’s DWD law, was dead on arrival. Thanks to our proactive efforts and a lack of interest in challenging the will of nearly 60 percent of the voters, the bill was never scheduled for a hearing and never made it out of the gate to begin the long legislative process.

SB 5378 sought to repeal a crucial portion of the DWDA, the section of the initiative stating that deaths under the Act do not constitute “suicide.” This bill was a thinly veiled attempt to gain access to information through our state’s open records policy to identify people who used the DWDA and to expose participating physicians.

If it had passed, SB 5378 would have made it possible for antichoice extremists to intimidate physicians and harass grieving families. The stage would have been set for hostile demonstrations at burials and memorial services and protests at physicians’ offices.

Because we are beginning a two-year legislative biennium, the bill will be reintroduced automatically in 2012. We will continue our efforts to prevent it from undermining our DWD law.

Efforts To Pass Medicine Return Bill Continue

Unfortunately, pharmaceutical industry lobbyists managed to defeat Washington’s Secure Medicine Return legislation this session. The legislation would have required drug producers to provide and pay for a safe, convenient drug take-back program in Washington. The program would help keep dangerous medications out of homes, reducing accidental poisonings, theft, teen drug experimentation, and avoid water pollution as well. C&C is an active member of the Take Back Your Meds coalition (www.takebackyourmeds.org), which continues to work on gathering new members, spreading the word with a goal of passing the bill in 2012.

Living Will Registry Shut Down

Although C&C was able to save the Washington Living Will Registry (LWR) from elimination in 2010, there was no hope of saving it from deep budget cuts made during the 2011 legislative session; the LWR came to an end on July 1.

The LWR was an innovative program hampered by a lack of adequate funding for educating the public about the program and, therefore, low participation. The good news is individuals who registered with the LWR will maintain lifetime registration with the U.S. Living Will Registry, a private corporation. Previous registrants do not have to resubmit documents.

In July registrants will be receiving a letter from the U.S. Living Will Registry with a new wallet card and stickers. The lifetime membership with the U.S. Living Will Registry will enable registrants to download, view, and print their documents, as well as update documents and make changes to their personal and emergency contact information.

If you are registered with the LWR and do not receive your new wallet card, contact the U.S. Living Will Registry at 1-800-548-9455 for assistance.

Medicaid Hospice Benefit Preserved

Even though the Governor’s budget proposed eliminating coverage for hospice services for Medicaid patients, the final budget included full coverage for Medicaid patients facing the end of life. C&C joined in a successful coalition effort to persuade legislators that this cut was misguided, cruel, and shortsighted.

Want to be Kept in the Loop?

Receive updates about special events and news alerts by joining our email list. Go to our website, www.CompassionWA.org, scroll down to the bottom of our homepage, and sign up online. We never sell, rent, or trade our email list!
Introducing C&C’s Medical Directors

Compassion & Choices of Washington is proud to have a high-caliber team of medical directors who provide expert support and guidance to our client support team and to physicians participating in the Washington Death With Dignity Act.

Tom Preston, MD, Senior Medical Director, is a retired cardiologist and esteemed professor emeritus at the University of Washington Medical School who practiced and taught cardiology for three decades. He was C&C’s first medical director and played a key role in creating the Initiative 1000 Coalition and then helping to lead the campaign. During his nearly 20 years of volunteering, he has also served on C&C’s board of directors and as a client support volunteer. Dr. Preston is at the forefront of the bioethical debate on patient autonomy and aid in dying and has written several books about the issue. He has been featured in news media across the country.

Richard Baker, MD, is a recently retired family physician and professor emeritus of family medicine at the University of Washington where he did research on medical education, health promotion, and disease prevention. He was also a professor of family medicine at the University of California San Diego and the University of North Carolina. Dr. Baker splits his volunteer service between C&C and IslandWood, an outdoor learning center, which fulfills his passions for freedom of choice and for environmental stewardship. He is also a client support volunteer and said that he “has been deeply moved by the courage of his clients and their families as they face death.”

Our newest medical director is Robert Wood, MD, a gay general internist who was very involved in HIV/AIDS care during the worst of the epidemic. These experiences led him to become involved in the Initiative 119 campaign in 1991 and then join C&C’s advisory committee a few years later. Last year, he agreed to a “promotion” and began volunteering as a medical director.

Dr. Wood was the highly regarded director of the HIV/AIDS control program at the Seattle & King County public health department, retiring in 2010 after 24 years. Along the way, he won multiple awards for his public service, including the Governor’s Public Service Award. In 2009, he became a clinical professor of medicine at the University of Washington.

“I became a volunteer medical director because AIDS strengthened my understanding of the extreme importance of helping people as comprehensively as I could ‘on their terms,’ including their right to obtain advice and help in making end-of-life decisions.”
Most people support their favorite charities by writing a check once a year. Some people go a step further, by planning their future charitable gifts.

If you have been helped by our services – or would just like to support our work – consider including a charitable “bequest” in your will. Bequests can take several forms, but they are a simple way to leave a legacy, and they offer tax advantages as well. Your attorney or our advisory committee member Steven Schindler, Esq., (see article to the right) can provide advice based on your personal tax and financial requirements.

When you make a charitable bequest to C&C, it enables your values and commitments to carry on in the service of others. For more information about making a bequest, please contact Carol Gipson, MA, Director of Development.

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.

Thanks from a Family Member

“We would like to thank you for all the support and comfort you provided to our aunt… She was glad that you were able to help… Please thank [your client support volunteer] for all her assistance to our aunt and to our family. May God bless you.”

New Advisory Committee Member
Attorney Steven Schindler

Steven, an Associate at Perkins Coie, represents individuals and families in personal and estate planning strategies and advises clients on estate and trust administration, probate, and the preparation of gift and estate tax returns. He also represents executors and administrators, trustees, guardians, and beneficiaries in estate and trust administration.

Steven holds a J.D. (magna cum laude) from Duke University and a Masters in Public Policy from Duke University. His professional and community leadership includes serving as Treasurer of the Real Property, Probate, and Trust Section of the King County Bar Association and on the Board of Directors at Powerful Schools, Inc.

We encourage anyone needing estate-related planning to contact Steven at the law offices of Perkins Coie, 206.359.6221.
Beda Herbison, LICSW, is a recently retired social worker who worked at the VA Puget Sound Health Care System in Seattle. Her interest in death and dying stems from many years of personal experience during the AIDS epidemic and 15 years of volunteering with the Shanti program, which provides one-on-one emotional support for people with life-threatening illness (among other services). Beda had a firsthand experience with C&C’s services; her father-in-law, who recently died of metastatic melanoma, utilized our client support services. Like many C&C clients, he acquired great peace of mind from having a “plan B” in place in case his suffering became unmanageable. Ultimately, he chose not to take the medication. Beda describes her work for C&C as “intense, honest, and loving,” calling it the “definition of compassion.”

Doug Schiebel, PhD, is a retired clinical psychologist and professor who came to the United States from Germany to study at the University of Washington. He went on to teach and practice in California and Arizona. After retiring, he and his wife of 50 years returned to Port Ludlow to live under the snowcapped Olympics, which remind him of the Bavarian Alps. Doug’s professional life was dedicated to stopping people from harming themselves, helping them realize their own strengths, and living more joyfully and assertively. He now uses his professional skills to support our clients. “Helping my clients and their families through the end-of-life process has been very meaningful and deeply rewarding for me,” says Doug. “When only pointless pain and suffering remain, hastening death can be an act of self-affirmation.”

Jenny Ruff moved to Seattle from California in 2010 and hopes to earn her Master of Social Work degree from the University of Washington. She has volunteered with hospice and various cancer organizations since she was 17. “I was not even aware of the law in Washington when I moved here,” says Jenny, “but, when I stumbled across C&C online, I knew I wanted to be a part of this. When people become seriously ill, so many things are taken away. The rights of patients to make their own end-of-life choices based on their own values shouldn’t be one of them.” Jenny’s mother’s fight against breast cancer has given her firsthand experience with what her clients’ families are dealing with as they come to terms with their loved ones’ terminal diagnoses. One of the most rewarding aspects of this work for Jenny is seeing the relief people experience when they gain control over the dying process.

For a decade of volunteering for Highline Home Health & Hospice, Monty Berke, MSW (who has also been a C&C client support volunteer for five years), was named the Home Care Association of Washington’s 2011 Volunteer of the Year.

Monty’s volunteer supervisor at Highline Home Health & Hospice described Monty as “reliable, creative, thoughtful, personable, grounded, intelligent, experienced, and a compassionate listener to patients and family members,” and having “the right soul for volunteer work.” We concur!
Two different patients limp into two different medical clinics with the same complaint. Both have trouble walking and appear to require a hip replacement. The first patient is examined within the hour, x-rayed, and booked for surgery the following week. The second patient sees his family doctor two weeks after requesting an appointment, then waits weeks longer to see a specialist. He then gets an x-ray which isn’t reviewed for another week. One month later, he finally has his surgery. Why the different treatment for the two patients? The first is a Golden Retriever. The second had Medicare.

“Our study does not support that the choice for PAD [physician-assisted death] reflects poor symptom management. In fact, in the view of family members, it does appear to meet patients’ preferences for control and avoidance of a period of declining function....this study adds to the evidence that the choice to pursue PAD does not appear to be due to, or a reflection of, poorer end-of-life care. Nor is the quality of death experienced by those choosing PAD any worse than for those not pursuing PAD; in some areas it is rated as better by family members.

Derek Humphry to be Keynote Speaker at 2011 Annual Meeting

This year our keynote speaker will be Derek Humphry, the author of *Final Exit* and the founder of the Hemlock Society USA in 1980. Derek is generally considered to be the father of the modern movement for choice at the end of life in America.

Derek is a British journalist and author who has lived in the United States since 1978, the same year he published the book *Jean’s Way* describing his first wife’s final years of suffering from cancer and his part in helping her to die peacefully. The public response to the book caused him to start the Hemlock Society USA in 1980 from his garage in Santa Monica. Years later, the Hemlock Society would become End of Life Choices and then merge with Compassion In Dying to become Compassion & Choices.

In 1991 he published *Final Exit*. Much to his surprise, it became the national #1 bestseller within six months. Since then it has been translated into 12 languages and is now in its fourth edition.

Although not affiliated with – and sometimes even at odds with – Compassion & Choices, Derek is still actively involved in the movement. Always interesting and sometimes controversial, Derek will provide our supporters and their guests with his perspective about the evolution of the movement for choice at the end of life in America.