



Catholic Directive Undermines End-of-Life Choices

Responding to lobbying by the National Right to Life Committee and others over the Terri Schiavo case, the United States Council of Catholic Bishops directed a change in the "Ethical and Religious Directives for Catholic Health Care Services" (ERDs), this applies to all patients receiving care at Catholic facilities, regardless of their religious beliefs, advance directives, or the wishes of their health care agents or family.

In keeping with the ERDs, Washington State Catholic health care providers have a long history of forbidding hospice nurses, social workers, and volunteers from discussing the option of aid in dying and prohibiting



Illustration by Brucie Rosch, provided courtesy of MergerWatch

referrals to Compassion & Choices of Washington. Some have even required their employees to sign an "oath" stating they will adhere to their employers' antichoice policies, putting their staff in direct conflict with professional and ethical standards concerning practicing patient-centered care and not abandoning patients.

All Catholic health care providers in Washington also legally prohibit physicians and pharmacists they employ from participating in the DWDA (although only while on their employers' premises), as well as prohibiting patients from taking life-ending medication while they are in Catholic facilities, such as nursing homes.

The new language in ERD 58 goes much further than existing practices of gagging employees and banning participation in the DWDA. For the first time, an ERD creates "an obligation to provide patients...medically assisted nutrition and hydration" in all instances except when the patient is actively dying. The revision defines artificial feeding tubes as "basic," not "medical" care, and makes them obligatory unless a patient is actively dying or has certain complications.

(continued on page 4)

Save the Date for C&C's 2010 Annual Meeting

October 23, 2010, 1 - 3 p.m.

Unitarian Church at 6556 -35th Avenue NE, Seattle, 98115

This year our keynote presentation will be something entirely different – a performance of the new play, "Demonstrate the Place of My Abode," by Lisa Koch, a well-known and very talented Seattle singer, songwriter, actor, and comedian.

"Abode" is an intimate look at her fun-loving father, the music he inspired, and a candid glimpse into Death With Dignity. Combining music, comedy, recollections, and a photo montage of her family, "Abode" is a touching and humorous tribute to a father and his courageous end-of-life choices. Thoughtful, moving, funny, and musical, it's a must-see for C&C supporters and their friends.



Lisa Koch

C&C's executive director, Robb Miller, will also provide a short report on C&C's recent activities, successes, and challenges. Following the performance, please join us for snacks and refreshments and a small end-of-life resource fair with representation from People's Memorial Association, Evergreen Hospice, Older Women's League, A Sacred Moment (green burials), and others.

Hospice & Death With Dignity

BOARD OF DIRECTORS

Terry Barnett, Esq., *President*
Joanne Brekke-Selk
Sheila B. Cook, *Editor*
Robert A. Free, Esq.
Alberta Golden, MLS
Judith Gordon, PhD
Pamela Hanlon, RN, Esq.
Arline Hinckley, ACSW, *Secretary*
Midge Levy, ACSW, *Vice President*
Catherine L. Longhi
Rusty Myers, LICSW
Bruce Parker, DMin
B. Kirk Robinson, *Treasurer*
Thomas Smith, MD

ADVISORY COMMITTEE

Michael Bonacci, MFA
Jonathan Gavrin, MD
Steven Ginsberg, MD
Molly Hoffman, MSW
Trudy James, MRE
Len Mandelbaum, Esq.
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

CLIENT SUPPORT LEADERSHIP

Richard Baker, MD, Asst. Medical Director
Gretchen Deroche, Volunteer Coordinator
Tom Preston, MD, Medical Director

STAFF

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

OFFICE VOLUNTEERS

Ruth Askey
Norma Beerweiler
Wendy Clarke
Joe Handelman
Iona Stenhouse

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.



During my ten years at Compassion & Choices of Washington (C&C), we have referred hundreds of patients to hospice, which we believe is an essential component of excellent end-of-life care. Because hospice enables the vast majority of its patients to die in their homes, it helps them maintain dignity and control at the end of life. If a qualified C&C client is not on hospice, that is usually our first recommendation.

The implementation of the Death With Dignity Act (DWDA) in Washington has been challenging for many hospice providers. While hospice has no legal role in the process, it is often the primary source of health care for dying patients seeking the option. Many hospices feel obligated to honor a patient's right to choose DWD.

Fortunately, many Washington hospice providers are continuing their commitment to patient autonomy regarding DWD. Some allow their medical directors to participate as the Consulting Physician, some allow their staff to be present when a patient takes life-ending medication, and most are referring clients to C&C. Because of the hospice philosophy to neither hasten nor hinder death, referring to C&C allows hospice to remain neutral on the issue while supporting the patient. In turn, C&C encourages patients to keep hospice in the loop about their DWD plans, because it plays an essential role in end-of-life preparations.

Unfortunately, there are a significant number of religiously affiliated and other hospices that are opposed to DWD and have adopted draconian policies around the issue. These hospice providers forbid their nurses and social workers to discuss the issue and often instruct them to refer the patient to his physician, who may or may not be willing to talk about it. Referrals to C&C are also strictly prohibited.

These kinds of restrictions are disrespectful to patients and are not authorized by the DWDA. They violate the principles governing professional social work practice and can lead to a patient feeling abandoned. The hospice/patient relationship is one that must be built on trust and honest communication.

Over time, anti-DWD hospices will come to terms with the issue and evolve, just as they did in Oregon, where even religiously affiliated hospices now provide Compassion & Choices of Oregon's brochures to patients who request information about DWD.

In the meantime, be assured that no hospice provider will ever deny services to a patient because he or she wants the option of DWD. Understand also that it is inappropriate and unprofessional for hospice staff or volunteers to judge, lecture, or undermine a patient who makes this legal end-of-life choice. You have the right to file a compliant, request a new hospice nurse, and even dismiss your hospice provider and transfer to another, assuming more than one is available.

For more information about hospice, a hospice referral, or advocacy regarding hospice and DWD, please contact our office.

Introducing C&C's New Board Members



Robert Free, Esq., served on C&C's Advisory Committee for many years before joining the Board of Directors this year. Bob and other lawyers from his firm, MacDonald, Hoague & Bayless, generously provided many *pro bono* hours authoring seven *amicus* briefs on behalf of survivors of C&C's former clients. These briefs described for the courts the differing realities of what happens to families when a competent, terminally ill person is granted, or forbidden, the choice of aid in dying. They were presented to the Washington and United States Supreme Courts as well as various lower federal courts. After 35 years practicing law, Bob is in the process of retiring and looks forward to teaching immigration law, his specialty, at the University of Washington next year.

Pamela Hanlon, RN, Esq., is a health care attorney and critical care nurse. She has seen firsthand how the lack of understanding and access to information about end-of-life choices affects terminally ill patients and their loved ones. Early in her nursing career, Pam published an article about her first experience advocating for a patient's right to a peaceful death. At the University of Washington School of Law, she studied under C&C's National Director of Legal Affairs, Kathryn Tucker, Esq. Pam now works with hospital and health care organizations implementing hospice and palliative care programs. More recently, she published an article in *Bar News*, the journal of the Washington State Bar Association, explaining how the Death With Dignity Act benefits the citizens of Washington. As a member of the Washington End-of-Life Consensus Coalition, she advocates for informed end-of-life choices through education and public outreach.



Rusty Myers, LICSW, recently rejoined C&C's board and has long been a member of C&C's "family." For twelve years, he was the part-time administrator for The Hemlock Society of Washington State (one of C&C's predecessor organizations) and was actively involved in the first attempt to pass an aid-in-dying initiative in Washington, the I-119 Campaign in 1991. In his full-time position at King County HIV/AIDS, Rusty facilitated support groups and conducted research interviews with HIV/AIDS patients. Currently, he co-teaches a course on end of life at the University of Washington and is working as a hospice social worker.

Website Maintenance Volunteer Needed!

We need help keeping our website up to date. Basic code writing experience is required. This is a volunteer opportunity that could be done from a home computer or at our downtown Seattle office a few hours a week. Call or email C&C for more information.

New Death With Dignity Overviews for Health Professionals

After a year and a half of experience with the Death With Dignity Act, C&C has compiled these succinct guides for health care providers. Go to www.CompassionWA.org/dwda.html, click on the Medical Provider's tab, and select the appropriate guide:

- Attending Physician
- Consulting Physician
- Nurse, Social Worker, or Other Health Professional
- Pharmacist
- Psychiatric Consultant (created by the Washington State Psychological Association)

Catholic Directive Undermines End-of-Life Choices (continued from page 1)

The directive conflicts with nearly all commonly used advance directives, such as C&C's and The Five Wishes, that provide an option to decline artificial nutrition and hydration in the setting of permanent unconsciousness or advanced dementia. It could also force patients to either accept feeding tubes or transfer to nonsectarian facilities. This extreme policy apparently applies to all patients, whether they are Catholic or not, who receive care in Catholic-run hospitals.

There are approximately 17 Catholic hospitals in Washington, and more than 30 percent of Washington patients are in Catholic facilities, which are required to comply with the new Directives. In some parts of Washington, such as Whatcom County, patients have few alternatives to a Catholic provider. And a patient in a medical emergency is taken by ambulance to the nearest hospital, not the nearest hospital that shares his values.

Hospitals owned and operated by religious organizations have won special exemptions – appropriately called “refusal clauses” – permitting them to use religious doctrine to guide patient care, while remaining eligible to receive public funding. Refusal clauses have proliferated at the federal and state levels. Increasingly, the patient's moral and religious convictions are taking a backseat to the beliefs of people charged with caring for their health.

Since United States courts have consistently accepted that mentally competent patients have a right to refuse care if their wishes are clear and documented, ERD 58 may well be illegal.

Alan Meisel, founder of the University of Pittsburgh's Center for Bioethics and Health Law, wonders if Catholic hospitals could be compelled by law to respect patients advance directives, regardless of the Church's moral stance. He says it is not clear whether the legally binding power of an advance directive would outweigh the Church's right to administer medicine in accordance with its beliefs. “[If] the hospital seeks to impose a treatment on a patient which that person does not want, to impose that treatment is battery,” he says, but adds a caveat: “One could say since you've admitted yourself to a Catholic hospital, that's a form of consent...If I were a patient with a directive,” he continues, “I would probably add to it that I didn't want to be taken to a Catholic hospital.”

Even if ERD 58 is not a violation of the law, it is a gross breach of accepted standards of medical ethics. No doctor or nurse in the United States may provide such unwanted nutrition and hydration without defying a well-established code of professional conduct, and it is likely that any provider who did so would lose his or her license. Physicians and nurses are bound by the same ethical obligations that govern all other members of their professions. They must obtain informed consent, honor patient autonomy, and offer medical care in line with clinical standards of their colleagues at secular institutions.

Some may argue that since Catholic hospitals are private institutions, the Vatican can impose any rules that it wants. The claim belies the inherently public nature of the American hospital system. Catholic hospitals – like virtually all other hospitals in the United States – are only able to function as a result of a swath of government handouts and subsidies. Medicare and Medicaid pay the bills of approximately half their patients. Federal funding supports the salaries of their medical residents. In reality, Catholic hospitals function as public entities that serve diverse communities and people of all faiths and traditions.

The ERDs have been around for a long time, and many Catholic hospitals and the physicians view them as a formality to be agreed to and then summarily ignored. Historically, the Church has looked the other way.

How all this is interpreted by Washington's Catholic health care providers and, more importantly, how it is accepted by consumers of Catholic health services, deserves to be carefully watched.

Catholic providers have attracted unwanted attention over this change in policy and have been trying to downplay the issue, claiming that situations when ERD 58 applies are exceedingly rare, which is true. But for those who believe their dignity requires health care providers to abide by their wishes to keep feeding tubes out of their bodies if they have no hope of regaining consciousness, “it's unlikely to happen to you” isn't good enough.

The Catholic Health Association of the United States, a voluntary membership organization representing

Until Catholic providers can answer the question, “Will you honor my choice to decline nutrition and hydration if I am in a persistent vegetative state?,” with an unqualified “yes,” C&C recommends that you take action to protect your end-of-life choices.

Catholic hospitals, long-term care, and other health care providers, released a statement which reads: "In the vast majority of cases, patients' advance directives will be honored. ...There may be the occasional situation, such as some patients in a persistent vegetative state, when what the patient is requesting through his or her advance directive is not consistent with the moral teaching of the Church. In these few cases, the Catholic health care facility would not be able to comply."

Until Catholic providers can answer the question, "Will you honor my choice to decline nutrition and hydration if I am in a persistent vegetative state?," with an unqualified "yes," C&C recommends that you take action to protect your end-of-life choices.

If you receive care at a Catholic hospital or facility, what should you do? Any patient currently receiving care in a Catholic hospital should immediately clarify with his or her doctor whether this physician will follow the patient's own end-of-life wishes regarding life-

sustaining measures, if they come into conflict with ERD 58. Additionally, you should also complete our new **Directive Regarding Health Care Institutions Refusing to Honor my Health Care Choices** (see insert), make copies, and then give one to everyone who already has a copy of your documents – especially your physician, health care agent, and family – with instructions to attach it to your existing directives.

Ultimately the reliance on Medicaid and Medicare revenues may nullify ERDs that undermine patients' legal end-of-life choices. On April 15, President Obama issued a memorandum directing the Secretary of Human Services to ensure that all hospitals participating in Medicare or Medicaid are in compliance with regulations to guarantee that patients' advance directives are respected. Until regulatory action kicks in, a legal ruling occurs, or legislation is passed to ensure your end-of-life wishes will be honored, we highly recommend the use of our new directive.

Arline Bovee (1920-2010): In Memoriam, With Appreciation

Arline Bovee was a longtime supporter of Compassion & Choices of Washington (C&C) beginning with her membership in the Hemlock Society of Washington.

She worked as physical therapist and was an active member of Shoreline Unitarian Church. Because she was familiar with our health care system and had only distant relatives, she was proactive about her decision to avoid aggressive and intrusive end-of-life care and counted on C&C to help uphold her wishes.

Following her move to the Seattle retirement facility, Exeter House, Arline effectively advocated for her own end-of-life wishes and encouraged other residents to learn about advance planning and C&C's services by arranging presentations for us.

In 2006 she developed major health problems and became a C&C client. She died peacefully in February, without undergoing prolonged treatment.

Arline's final act of generosity was to bequeath one-seventh of her estate to C&C and six other nonprofit organizations. We are very grateful for her support during her lifetime and for remembering us in her will.

Consider a Planned Gift to C&C!



When you make a planned gift to C&C, it enables your values and commitments to carry on in the service of others. You can make their journey easier and enjoy the

satisfaction of knowing your money or the money of those who wish to honor you will be used to uphold choice at the end of life. Here are two easy ways you can help:

- Arrange for a memorial request. Consider placing a statement in your obituary suggesting that memorial donations or remembrances be sent to Compassion & Choices of Washington, PO Box 61369, Seattle, WA 98141.
- Remember C&C in your will. Consider leaving a percentage of your estate or a contribution for a specific amount to Compassion & Choices of Washington.

For more information about these and other ways you can create a lasting legacy through planned giving to C&C, please call our office.

Client Support Volunteer Spotlight

Seattle

Risa Denenberg, ARNP, joined our client support team a year ago and brought a great deal of experience with death and dying. She worked with AIDS patients, as a hospice nurse, and then as a palliative care nurse practitioner. While working at Harborview Medical Center, Risa's patient was the first one at Harborview to request Death With Dignity (DWD), and she was present when C&C volunteers arrived to provide her patient with advice and support. Risa noticed that even though her patient declined too quickly to complete the DWD process, having the option provided great comfort. The experience really affected Risa and made her realize that volunteering with C&C could have a real impact. "In my role as a client support volunteer (CSV), I have a higher level of intimacy with people at the end of life than I had as a nurse practitioner," says Risa. "Being present for a death is an honor, and a DWD death is as sacred to me as any death I have witnessed." Risa is now working in women's health and feels that volunteering with C&C helps her stay tied to the field she loves. She also assists with the training of new CSVs and is an instructor at Shoreline Community College.



Cynthia Heft lives and works in Bellingham with her husband at their design and build company. She loves the natural beauty of the Northwest corner of Washington. After reading an article in the Seattle Times about patients having difficulty



Bellingham

accessing to the Death With Dignity Act, Cynthia felt compelled to help, and that led her to volunteer for C&C. She trained with Arline Hinckley, an experienced CSV and C&C Board Member, and felt that her introduction to client support could not have been better. Cynthia feels privileged to help and says that "when you are invited into the dying process with a family, the reward of volunteering is immediate and intimate. Offering support and answers to families struggling with end-of-life issues is a tremendous relief to the family."

Rosemary Harer, MA

is a psychotherapist in private practice for the last 31 years with a focus on complex Post Traumatic Stress Disorder (PTSD) issues, crisis intervention, and grief and loss issues. She has a long history of volunteering, and



Seattle

much of her past volunteer work was with terminally ill people. "I was especially drawn to C&C, first through working on the I-1000 Campaign, and after that passed, chose to be a client support volunteer. I have always been a strong advocate of the freedom of choice, and specifically for this choice. Being able to be part of an organization that helps people feel safe, informed, and in control of their end-of-life choices is something I am deeply committed to and believe in."

South King Co.



Jackie Klakken is a medical assistant in a pulmonary clinic. She became aware of C&C when one of her patients was working with C&C to pursue DWD, but was unable to complete the process before dying. The patient told his family ask Jackie to learn to help other people, and

this moved her to volunteer for C&C. Jackie says that "volunteering has helped me gain information and experience about the end of life that has enriched my career. It has also given me the tools to help patients and C&C clients with some of the most important decisions of their life. They have shown me how unique each individual's experience with death is, based on their own backgrounds, beliefs, and values."

Client Support Volunteers Needed

in Olympia, Centralia, Port Angeles, Sequim, and Eastern Washington. For information about volunteering, go to our website and click on "Get Involved."

Congratulations, Amber Wade, MSW



C&C's Director of Client Support graduated with her Masters of Social Work degree at the University of Washington. Amber began working at C&C in 2007 as our Administrative Assistant and attended classes during the evenings and weekends. She had the opportunity to do her Advanced Practicum

at C&C under Midge Levy, ACSW, C&C's Vice President. Amber is currently pursuing licensure.

On The Lighter Side

"A recent survey stated that the average person's greatest fear is having to give a speech in public. Somehow this ranked even higher than death, which was third on the list. So, you're telling me that at a funeral, most people would rather be the guy in the coffin than have to stand up and give a eulogy."

~ Jerry Seinfeld



A man rushed into a busy doctor's office and shouted, "Doctor, I think I'm shrinking!" The doctor calmly responded, "Now settle down. You'll just have to be a little patient."

A married couple was sitting in their living room, and he said to her, "Just so you know, I never want to live in a vegetative state dependent on some machine and fluids from a bottle. If that ever happens, just pull the plug." His wife got up, unplugged the TV, and threw out all his beer.

Special Thanks To:

Our dedicated client support volunteers; client support team coordinator, Gretchen DeRoche; medical directors, Tom Preston, MD, and Dick Baker, MD; outreach coordinator, Midge Levy; and fundraising committee members, Deborah Cohen, Rosemary Harer, and Ruth Marten Scott for the many hours they volunteer every month.

Zeeks Pizza for more than ten years of generous in-kind support, including providing pizza and salads at our monthly client support team meetings. Zeeks now has six Seattle locations (206.285.TOGO) and three on the Eastside in Bellevue, Kirkland, and Issaquah (425.893.TOGO). Or order online at www.zeekspizza.com.

Our progressive foundation donors: The Dudley Foundation, Riverstyx Foundation, Older Women's League, Transformation Fund, and Chester Woodruff Foundation.

Steven J. Schindler and Perkins Coie for invaluable, pro-bono legal assistance handling a recent bequest.

Our reliable, efficient office volunteers: Ruth Askey, Norma Beerwiler, Wendy Clarke, Joe Handelman, and Iona Stenhouse.

Mike Summy, CPA, for ongoing technical support for the custom-made, donation-tracking/ mailing list software program he created and donated to C&C, valued at approximately \$20,000 (mfsummy@seanet.com, 206.523.1840).

Our client support volunteer and public speaker, Dawna Zullo, for numerous outreach activities and presentations to retired veterans' groups and other organizations in Clallam County.

Sheila Cook, Board Member and editor, and one of the founders of C&C, for excellent proofreading and editing of all our documents.

Minuteman Press for providing a 15 percent discount and much more (206.448.8919, www.belltown.minutemanpress.com, located in downtown Seattle).

IN THIS ISSUE

Catholic Directive	1
Robb Report - Hospice & DWD	2
New Board Members	3
New DWD Overviews	3
Arline Bovee & Planned Giving	5
Volunteer Spotlight	6
Special Thanks	7

Research Underscores the Importance of Advance Planning



A new, multistate study in the July 2010 *Journal of the American Geriatrics Society* found that patients with Physician Orders for Life-Sustaining Treatment (POLST) forms, saying they wished to receive care that primarily focused on relieving their pain and suffering, were 59 percent less likely to receive unwanted treatments such as hospitalization than those who had only a Do Not Resuscitate (DNR) order. The study also showed that for patients who wanted intensive care, POLST helps ensure they will receive full treatment.

The goal of POLST is to honor treatment preferences of those with advanced illness or frailty. POLST translates patients' wishes about a range of treatments into medical orders that are easily understood by health care providers and can be acted on immediately. To request a free copy of the bright green form, please contact our office.

A recent study in the February 2010 *Journal of the American Medical Association* confirms that written advance directives, DNR orders, and orders to forgo artificial nutrition and hydration (such as POLST) are associated with lower rates of feeding tube insertions, suggesting that advance care planning has an important role in the reduction of potentially unnecessary procedures.

C&C's free advance directive packet includes a Health Care Directive (Living Will) and Durable Power of Attorney for Health Care combined into one document that every adult should have. Download the packet from our website, www.CompassionWA.org, or call our office to receive one in the mail.

