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# Update

## Major breakthrough in ALS research gives patients hope for the future

**A**myotrophic lateral sclerosis (ALS), a fatal neurodegenerative condition that paralyzes its victims, has so baffled researchers that there is currently no effective treatment or cure to stop its progression. Sometimes referred to as Lou Gehrig's disease or motor neuron disease, ALS affects nerve cells in the spinal cord and brain that control voluntary muscle movement. Until now, scientists were unsure about the cause of this nerve degeneration or even if the various types of ALS shared a common disease process.

Recently, however, breakthrough research conducted by a large team of scientists at Northwestern University

Feinberg School of Medicine has finally uncovered the common cause of all forms of ALS. Their findings are published in the scientific journal *Nature*. [Han-Xiang Deng, et al., "Mutations in UBQLN2 cause dominant X-linked juvenile & adult-onset ALS and ALS/dementia," *Nature*, 9/8/11 (online version: 8/21/11)]

The cause of ALS is "a broken down protein recycling system in the neurons of the spinal cord and brain." Normal neuron functioning is dependent on efficient protein recycling in cells. In ALS patients, cells cannot repair or maintain themselves and become severely damaged. Researchers found "robust evi-

dence" that this breakdown occurs in all three types of ALS: hereditary ALS, called familial; nonhereditary, called sporadic; and ALS which affects the brain, called ALS/dementia.

"This opens up a whole new field for finding an effective treatment for ALS," explained Teepu Siddique, M.D., one of the study's senior authors. "We can now test for drugs that would regulate this protein pathway or optimize it, so it functions as it should in a normal state."

The study's findings will likely impact the development of effective treatment protocols for other neurodegenerative

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## Massachusetts targeted for initiative drive in 2012

**T**he Massachusetts attorney general has given the okay for doctor-prescribed suicide advocates to gather signatures that would put an initiative legalizing assisted suicide on the state's ballot in 2012. The Massachusetts Death with Dignity Act initiative is modeled after the doctor-prescribed death laws in Oregon and Washington—the only two states to pass such laws.

The Hemlock Society spin-off groups Death with Dignity National Center (DWDNC) and Compassion and Choices (C&C) are behind the Massachusetts initiative drive. Last year, Peg Sandeen, head of the Oregon-based DWDNC

confidently announced plans to target New England States. First, they would introduce an assisted-suicide bill in Vermont followed by a ballot initiative campaign in a then unnamed New England state. [DWDNC Press Release, 11/3/10]

But, in spite of their polling and research indicating a likely victory in Vermont, assisted-suicide advocates failed to move the prescribed-death bill during the 2011 legislative session. This was a huge disappointment for these activists who were banking on an easy Vermont victory to jumpstart their initiative drive.

Undeterred, DWDNC and C&C have proceeded with

their initiative plan. They formed the Massachusetts Death with Dignity Coalition (MA-DWDC) to oversee the statewide initiative campaign called "Dignity 2012." On August 24, they filed papers with the state attorney general's office and, on September 7, were given the certification needed to begin gathering voter signatures. *Boston Herald*, 8/4/11; *Berkshire Eagle*, 9/7/11]

According to the attorney general's office, the MA-DWDC must gather and file 68,911 valid signatures by December 7, 2011. The initiative would then go to the legislature. If the legislature fails

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## Vermont official discusses prescribed suicide as a way to cut health care costs; governor continues to lobby for legalization in 2012

Last May, Vermont passed a law creating a statewide, single-payer health care system. Titled Green Mountain Care, the system covers all 620,000 state residents. When he signed the new system into law, Vermont Governor Peter Shumlin said the system would cut health care costs without compromising health care quality. [Governor’s Press Release, 5/26/11]

In July, during a “conversation” with the *Addison County Independent* newspaper, Stephen Kimbell, commissioner of the Vermont Department of Banking, Insurance, Securities and Health Care Administration, talked about two sure ways for Vermont to cut health care costs. A subsequent *Independent* editorial on Kimbell’s comments, explained the two ways as follows:

Passing a law that allows physicians to help end a patient’s life under very controlled circumstances, known as “death with dignity,” is one such measure that could help (an effort was tried this past [legislative] session but postponed until next year).

Another is approving some type of rationing measures, as Oregon has done, that help control health care costs. [Editorial, *Addison County Independent*, 7/18/11]

When Governor Shumlin was later asked what he thought about Kimbell’s controversial comments, he responded, “I’m not going to comment because I wasn’t part of the conversation.” He added that he did not believe that “Death with Dignity is a way to control costs.” [truenorthreports.com, 8/17/11] Shumlin, a staunch assisted suicide supporter, was recently quoted as saying, “I’d very much like to be the governor who signs it into law.” [Death with Dignity National Center Blog, 8/12/11]

True Dignity Vermont (TDVT), a broad-based coalition of groups and individuals opposed to doctor-prescribed suicide, said Kimbell’s comments reveal “a dangerous underlying motive behind the push to legalize assisted suicide” because “it is so much cheaper than care.” TDVT pointed out on its web site that if Shumlin really disagreed about assisted suicide’s cost-cutting function, “why has

he left this man in charge of implementing a health care plan Vermonters will have no choice to decline?” Furthermore, TDVT questioned how the “real choice” Shumlin says prescribed suicide gives to patients could ever co-exist with a state-funded health care plan that is clearly focused on cutting costs. “Legal assisted suicide is inherently destructive of choice, even in good times, and very obviously in bad economic times like these.” [True Dignity Vermont, Blog, 8/18/11]

During the same press conference that Shumlin was asked about Kimbell’s comments, the governor was also asked if the bill to legalize doctor-prescribed suicide that had failed to advance during this year’s legislative session would, in fact, pass during the second session in 2012. Shumlin replied, “I don’t know. The votes aren’t there in the Senate right now.” [Video, truenorthreports.com, 8/17/11] But later that day, Shumlin told the bill’s supporters that he is “spending a lot of time” lobbying senators to pass the bill. [Video, vtdigger.org, 5/17/11] ■

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diseases like Alzheimer’s disease and other forms of dementia as well as Parkinson’s disease. These conditions are also characterized by a breakdown in the recycling of damaged or “misfolded” proteins in cells.

Siddique has been researching ALS for over 25 years. “It was one of the most difficult problems in neurology and the most devastating, a disease without any treatment or known cause,” he said—until now. [Northwestern University, Press Release, 8/21/11] ■

**Editor’s note:** It is not uncommon to see ALS patients being interviewed by the media in locations where euthana-

*sia and assisted-suicide advocates have been working to change laws banning induced-death practices. These patients usually say they want to hasten their deaths because they fear the future and feel utterly hopeless since there is currently no effective treatment to stop ALS’s progression. Unfortunately, right-to-die groups often use these vulnerable patients to advance their agenda and unnecessarily reinforce those patients’ worst fears. Tragically, some ALS patients become assisted-suicide statistics with the all-too-willing help of US groups like the Final Exit Network and Compassion & Choices or the Swiss assisted-suicide clinic, Dignitas.* ◆

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to enact the measure by the first Wednesday in May 2012, advocates must garner another 11,484 voter signatures by early July 2012 in order to have the measure placed on the ballot in November. “An initiative petition, if ultimately passed by the voters, becomes the equivalent of a statute” said Attorney General Martha Coakley. [Press Release, MA Attorney General’s Office, 9/7/11]

But doctor-prescribed suicide advocates are in for a real battle from a strong coalition of organizations and individuals who oppose assisted suicide for diverse reasons, including the fact that it threatens the rights of all vulnerable patients to receive truly effective and compassionate care. ■

# Campaign for VSED puts vulnerable patients at risk

Rita L. Marker

“**M**om, what would you like for your last meal?”  
When we think of someone ordering a last meal, it’s always been within the chilling context of a condemned prisoner.

But that’s no longer the case. Articles now describe last meals before something called VSED, short for voluntarily stopping eating and drinking. And it’s being suggested for those who have decided it’s time to die, no matter what their physical condition may be.

Bizarre? Yes.

Unbelievable? Tragically, no.

Positive descriptions of such deaths are increasingly appearing in medical publications, law journals and the popular press as the following illustrate:

**Estelle** – According to her daughter who writes for the *New York Times*’ “New Old Age” blog, Estelle “wasn’t dying of anything.” With her daughter’s help, Estelle searched for ways to “organize her own death.” Together, they looked into various options before arriving at a decision. Proud of the results, her daughter later wrote, “Our study of what is known as V.S.E.D., or ‘voluntarily stopping eating and drinking,’ was impressive for amateurs, if I do say so myself.” [*NY Times*, 12/15/08]

**Virginia** – Like Estelle, Virginia was also in her 80s and had no life-threatening condition. And, like Estelle, Virginia’s adult child (a son who is a physician) helped her research ways to end her life. “I bought *Final Exit* for her and we read it together,” he wrote in a medical journal article. On her 85<sup>th</sup> birthday, she celebrated with her family at a party with all the trimmings. Following that, “she relished her last piece of chocolate, and then stopped eating and drinking.” [*JAMA*, 7/20/94]

**Lily** – After seeking advice from a suicide advocacy group and with support from her family, Lily, in her 70s, stopped eating and drinking. According to her daughter, she ate her last bite—homemade raspberry ice cream—and then began the process of death by dehydration. [*Sunday Times*, 3/0/09]

Those who advocate VSED say it’s painless, implying that a person just slips peacefully away. Several months ago, Compassion & Choices (the assisted-suicide advocacy group formerly called the Hemlock Society) launched a nation-wide campaign to promote VSED as a legal means to hasten death. In their promotional material, they describe it as a “gentle, natural passing.” [Compassion & Choices, “Peace at Life’s End, Anywhere” brochure, 9/11]

However, that’s far from true.

Death from VSED is caused by dehydration and takes anywhere from five to twenty-one days to occur. During that time, a number of very unpleasant and painful symptoms occur. Without powerful pain medication and drugs to control such things as seizures, the process can be truly gruesome, resulting in what has been referred to as “bad dehydration.” [*Widener Law Review*, 2011]

Estelle’s daughter explained that her mother had received medical support such as sedatives as she died. Virginia’s physician son arranged for her to have adequate medications to control discomfort. However, even with such medical interventions, a brutal death can take place. Local doctors were supportive of Lily’s decision and provided her with morphine and a sedative. But her daughter explained that, before Lily’s dehydration death, she was howling with anguish.

Some have asked if VSED is against the law. After all, since it’s intended to cause death, it is suicide. However, neither suicide nor attempted suicide is criminalized in any US state. Many years ago, penalties against attempted suicide were removed—not for the purpose of permitting suicide—for the purpose of *preventing* suicide. Penalties were removed so people could seek help in dealing with their problems without risk of being prosecuted.

But that laudable purpose has led to unintended consequences.

Now, some medical and legal publications are suggesting that health care professionals have an obligation to inform patients about the availability of VSED as an end-of-life option. [*AJN*, 9/09; *Widener Law Review*, 2011]

This poses a clear and present danger to vulnerable people—not just to those who have been diagnosed as terminally ill.

Nursing home residents, the frail elderly and people with disabilities are at particular risk for being offered the option of VSED—followed by the opportunity to choose their last meal.

And what can we expect next?

The words of euthanasia advocate Dr. Philip Nitschke give an indication of the future. He discussed the death of a disabled 60-year-old woman: “It is disgusting that the only option Margaret had left was to deny herself fluids and food and engage in a macabre process of slow torture and death.” He then suggested another option: “When their quality of life gets so bad that death is their chosen course, they need simply to go to the cupboard and legally take the drugs that will give them a peaceful and reliable death.” [*Bioedge*, 4/12/10] ■

**Rita L. Marker** is an attorney and the executive director of the Patient Rights Council. She is also the author of the book, *Deadly Compassion: The Death of Ann Humphry & the Truth About Euthanasia*.





# Terminal Illness: What does it mean?

Dr. Kenneth R. Stevens, Jr.

“My doctor tells me I’m terminal!” Mr. Jones blurted out to me in front of his wife. Mr. Jones had been referred to me because he had just been diagnosed with cancer in his right lung that had spread to his brain. Increasing headaches had caused him to see his doctor. CT scans of the brain showed two abnormal tumor masses in his brain, and further medical evaluation found the primary cancer in his lung that had spread to his brain.

I am a cancer specialist in radiation oncology. I have evaluated and, when appropriate, treated thousands of patients with cancer since 1967.

Mr. Jones was in his mid-fifties, married, with two married children. As I evaluated him, he did not outwardly appear ill. He was not having any breathing problems and, except for headaches, the tumors in his brain were not causing any neurological or mental problems. Yet, his doctor had told him and his wife that he was “terminal.”

What did his doctor mean? What does any doctor mean when informing a patient that he or she is terminal, or has a terminal condition?

Terminal means “the end,” and is a term used for many things: train terminal, computer terminal, etc. When used medically, terminal has an ominous and terrifying meaning. It means “this is the end of your life,” “your life is over,” “you have no hope of living much longer.”

How does a doctor come to the conclusion that a person is terminal or has a terminal illness?

Although most commonly used to refer to patients with cancer, “terminal” can also be used for other medical conditions. A patient’s terminal status can be dependent on treatment. A person with severe insulin-dependent diabetes mellitus could be considered terminal if they did not take insulin appropriately. However, with proper insulin treatment and diet, they can live a long time, even many decades. Patients with kidney failure requiring dialysis would die in a few days without dialysis; in that sense they may be considered terminal, but with dialysis they can live many years.

A close relative of mine was informed by her doctor that she had terminal pulmonary fibrosis and required supplemental oxygen. Upon hearing that ominous message, she notified her family of her diagnosis. All of her close family (siblings, children and grandchildren) traveled to be with her for one last time. It was quite a reunion. She, her husband, and family members were terribly distraught with her doctor’s medical opinion that she was terminal. “How long do I have, now that I am terminal?” she would ask me.

Today, four years after she received the “terminal” diagnosis, she still has terminal pulmonary fibrosis that requires constant supplemental oxygen and still lives in her home with her husband, who has his own significant medical problems. Family members and nurse’s aides spend time caring for her and her husband. She keeps speaking and focusing on her “terminal” illness—“How much longer do I have?”—yet she continues to enjoy the companionship of her large family, and they

appreciate that she has lived four years with a “terminal” illness.

I recently became acquainted with a man who told me the following story.

In August 2004, he had imaging studies done to evaluate him for kidney stones. Those imaging studies showed abnormalities in his liver. Further imaging studies showed 13 tumors in his liver and over 70 tumors throughout his lungs. Biopsy of his liver showed adenocarcinoma, a very advanced cancer. Specialized PET/CT scans showed his liver and lungs to “light up like a Christmas tree,” indicating widespread active cancer. His doctor told him, “You’re not going to last long.” He and his wife were told that he was terminal, that he would probably be dead in a month and a half and would not be alive for the next Christmas.

With that awful information from his doctors, he informed his employer, who changed his computer company management position to a less stressful one. Within two weeks of receiving the terminal diagnosis, he and his wife sold (at garage sales) or gave away an estimated \$20,000 of his tools and books in order that his wife would be unburdened of his stuff and to help prepare her for life without him. They sold his things for ten cents on the dollar and made arrangements for his burial plot in another state. They even contacted a realtor and almost sold their home, but three of their children still lived there.

He was puzzled because he did not feel ill from the liver or lung tumor abnormalities. He asked for clarification of the diagnosis. He thought, “There is no way I am going to die, I feel too good.”

Another biopsy of the liver was obtained. Seven different pathologists reviewed the tissue. Some pathologists questioned the accuracy of the original adenocarcinoma diagnosis, while others did not. The pathology slides and tissue were sent to a specialist in Boston, who said it was classic “epithelioid hemangioendothelioma” involving the patient’s liver and lung. This correct non-terminal diagnosis occurred about a month after the original terminal diagnosis. The man consulted other cancer specialists about his new diagnosis. Some wanted to give him chemotherapy, and others were not certain what to do. Up to that point, he had not received cancer treatment of any kind.

In the past seven years he has had CT scans of his chest and abdomen every six months. The abnormalities in his liver and lungs are still present but have not changed in number or in size. He has continued to work for a computer company and misses the tools that he sold at a great discount or gave away in garage sales when he was informed he was “terminal.”

After the original diagnosis, he and his wife made very hasty decisions that financially cost them dearly. Since they live in Oregon, that terminal diagnosis would have qualified him for doctor-prescribed suicide, a practice that is legal in both Oregon and Washington State. Tragically, he could have ended his life early and before he received the correct non-terminal diagnosis. In doing so, he and his family would have missed out on the past seven productive and healthy years, and even more years in the future.

In the mid 1970s, I had a patient who turned out to have a similar story. She was 30 years-old and had a large tumor in her liver that had spread to the central portion of her chest and was blocking the veins to her heart. She was also told that she had liver

cancer that had spread to her chest. She was told she did not have long to live. Yet, she lived over 20 years.

Twenty-three years ago, an 18-year-old college student was diagnosed with the most malignant type of brain cancer. I had the privilege of giving radiation treatments to his brain following removal of the cancer. Many doctors did not expect him to survive long, or if he survived they predicted that the tumor and treatments would significantly affect his brain function. However, he surprised them when he

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### Tragically, he could have ended his life early and before he received the correct non-terminal diagnosis.

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graduated from college, then attended and graduated from law school, passed the state bar exam, married, had two children, and was elected to his city’s council. He lived a very successful and productive life for over 20 years from the time of his terminal diagnosis.

There are many reported instances of patients outliving the terminal diagnoses and prognoses of their doctors. Dr. Jerome Groopman, M.D., in his books *The Anatomy of Hope* and *Second Opinions*, describes many patients who have overcome and outlived their terminal diagnoses.

A few years ago, Art Buchwald, a humorist best known for his long-running column in *The Washington Post*, amazed himself and others by surviving five months in a hospice program with liver cancer and kidney failure. Well enough to leave the hospice,

he survived an additional 6 months before dying of kidney failure.

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So, what happened to Mr. Jones, the man I first told you about with the lung and brain tumors? After evaluating the extent of Mr. Jones’ tumors, I offered radiation and chemotherapy to shrink the tumors. He accepted that recommendation and successfully completed the treatments with his tumors markedly decreased in size. He lived to spend two very productive years with his wife and children. They traveled together, and he lived to see the arrival of two additional grandchildren. Both he and his wife were very grateful for his prolonged and very functional life.

In talking with them, I recall that they—Oregon residents—did not understand why anyone would be interested in unnaturally shortening their life with doctor-prescribed suicide. They were totally opposed to its legalization.

My 44-year experience as a doctor for many thousands of patients with cancer has made me realize that it is very difficult to predict the life expectancy of a particular individual. Doctors can make generalized predictions regarding probability of death for a group of patients in a particular period of time, but that is a probability based on the group as a whole and not on specific individuals within the group. There is great variability in the course of an illness, particularly in those who are predicted to die many months from now. ■

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## Dutch doctors expand definition of “unbearable suffering” and compel colleagues opposed to euthanasia to refer patients to willing doctors

In his outstanding investigative book on Dutch euthanasia practice, entitled *Seduced by Death*, Dr. Herbert Hendin, a noted psychiatrist, wrote:

The doctors who help set euthanasia policies are aware that euthanasia is basically out of control in the Netherlands. They admitted this to me privately. Yet in their public statements and articles they maintain there are no serious problems. They not only attempt to suppress dissent from domestic critics, but actively work to promote and normalize euthanasia. [Hendin, *Seduced by Death: Doctors, Patients, & the Dutch Cure*, (New York: W.W. Norton & Company) 1997, pp. 14-15]

The truth of Hendin’s words became especially clear this summer when the board of the Dutch Medical Association (KNMG) adopted the position paper “The role of the physician in the voluntary termination of life.” The new 61-page policy—available online—became effective on June 23, 2011.

According to the KNMG, the “statutory framework and the concept of suffering” contained in the Dutch 2002 law legalizing euthanasia and assisted suicide “are broader than their interpretation and application by many physicians today.” Therefore, as patients get older, they can have an array of worsening medical problems that are not life threatening, but taken together can be considered “unbearable suffering,” making those patients legally eligible for an induced death. [KNMG position paper, p. 40]

Essentially, the KNMG has greatly extended the boundaries of what can be considered unbearable suffering, a requirement under the euthanasia law. As reported by Radio Netherlands, such suffering now includes “poor eyesight, deafness, fatigue, difficulty walking and incontinence as well as loss of dignity, [social] status, financial resources, an ever-shrinking social network and loss of social skills.” KNMG’s chairman, Arie Nieuwenhuijzen Kruse-

man, surprisingly admitted in an interview that the task of determining euthanasia eligibility by adding up the various new “suffering” factors could be “extremely difficult.” “It’s quite possible,” he said, “that the same constellations of factors would be experienced as unbearable and lasting suffering by one patient but quite tolerable by another.” [Radio Netherlands Worldwide, 9/8/11]

While the KNMG makes it clear in the new position paper that doctors can refuse to engage in euthanasia and assisted suicide, it also asserts that doctors have a “moral and professional duty” to refer patients in a timely fashion to doctors who will end their lives. Moreover, if a patient is not eligible for euthanasia and decides on his or her own to stop eating and drinking, then “the physician is obligated, in such cases to supervise the patient and alleviate the suffering [from dehydration] by arranging effective palliative care.” [KNMG position paper, pp. 40-41.] ■

## UK judge rules minimally-conscious patient has the right to live

In a landmark ruling, British High Court judge Mr. Justice Baker has denied a petition from the family of a 52-year-old, minimally-conscious woman to withdraw her food and fluids so she would die.

The woman—known only as M—suffered brain damage after she contracted viral encephalitis in 2003. She was initially diagnosed as being in a persistent vegetative state (PVS). As a result of new brain testing technology, M’s diagnosis was upgraded four years ago. She is now deemed to be in a minimally-conscious state (MCS). Justice Baker’s ruling was the first time a British court determined whether an MCS patient could be dehydrated to death. Prior food & fluids cases dealt with patients diagnosed or misdiagnosed as PVS.

During the hearing, M’s family offered highly emotional testimony, stat-

ing M had stated prior to her brain damage that she would not want to live totally dependent on others. Justice Baker acknowledged the family’s sincerity, but dismissed their claim. “...I find that [M’s] statements were not specifically directed at the question that now arises... nor do I find that I can consider those statements as a clear indication some eight years from the onset of her illness of what M would now want to happen.” [Court of Protection, Case No. 1182483, Decision, 9/28/11, 249-250]

“In my judgment,” the judge ruled, “the importance of preserving life is the decisive factor in this case.” Based on testimony provided by M’s caregivers, the judge found, “M does have positive experiences and that, although her life is extremely restricted, it is not without pleasures, albeit small ones.” Further-

more, the judge held, “there is a reasonable prospect that M’s positive experiences and quality of life can be extended by changes to her care plan that carefully expose her to increased stimulation.” “I have therefore come to the clear conclusion that it would not be in M’s best interests for ANH [artificial nutrition and hydration] to be withdrawn.” [251-252]

Caregivers had testified that M cried when the Elvis Presley song “Always on My Mind” was played, but smiled at the song “Tiger Feet” by Mud. One doctor told the court that M could push a buzzer when asked to do so. [Daily Mail, 9/29/11]

New high density EEG research on MCS patients has found that they dream and have sleep brain activity like normal, healthy subjects. [Brain, 8/11] ■



## News briefs from home & abroad . . .

- **Hawaii:** The assisted-suicide advocacy group Compassion & Choices (C&C) is at it again pushing what it calls “aid in dying” in Hawaii. Its PR strategy is blatantly obvious: If you say it’s so, people will think it’s so—even though it really isn’t so.

On September 14, C&C, in conjunction with the Hawaii Death with Dignity Society, ran a full-page ad in the *Honolulu Star Advertiser* claiming that an obscure 1909 statute already makes doctor-prescribed suicide legal in the state and announcing a “free conference” featuring a panel of experts who will “discuss this important issue.” [Ad, *Star-Advertiser*, 9/14/11]

The “conference,” hosted by Hawaii’s House Majority Leader Blake Oshiro at the State Capitol, was held on October 5. Led by C&C’s legal director, Kathryn Tucker, the conference basically consisted of a panel discussion by pro-assisted suicide activists and supporters offering misinformation rather than an unbiased airing of ideas. C&C issued an immediate press release, entitled “Expert Panel Concurs: Hawaii Physicians Can Provide Aid in Dying.” That release was reprinted in various newspapers and on web news sites, including one that ran the headline, “Hawaii rules physicians can provide aid in dying.” [C&C Blog Press Release, 10/5/11; *Travel News*, 10/8/11]

According to Karen DiCostanzo, president of Aloha Life Advocates, the statute that C&C claims legalizes doctor-prescribed death was enacted in 1909 so that doctors could use non-traditional/herbal drugs to combat diseases like leprosy, tuberculosis, and asthma—not to prescribe intentionally lethal drugs. Regarding C&C’s claim that the statute legalizes assisted suicide, DiCostanzo wrote, “Of course, this begs the question: If physician-assisted suicide is ‘already legal’ in Hawaii, why have suicide law proponents been trying—unsuccessfully—to legalize it for the past 10 years?” [*Hawaii Reporter*, 10/6/11]

C&C used a similar strategy in Idaho last year, with Kathryn Tucker declaring that assisted suicide was already legal because Idaho had no law explicitly banning the practice. But that strategy totally backfired when the Idaho legislature responded by quickly passing a law to unequivocally prohibit suicide assistance. [See *PRC Updates*, 2010, no. 3 & 2011, no. 2.]

- **Canada:** A law banning assisted-suicide is currently being challenged in two separate lawsuits. The first one, filed last April in British Columbia (BC) by the BC Civil Liberties Association, is due to be heard in the BC Supreme Court on November 14. The case challenges the law’s constitutionality on behalf of the relatives of Kay Carter, 90. In January, Carter traveled with her daughter to Switzerland

to die at the assisted-suicide clinic Dignitas. In June, Gloria Taylor, a BC grandmother with ALS (Lou Gehrig’s disease), joined the case. She maintains that she can’t afford a trip to Switzerland but still wants to die when and where she chooses, and with a doctor’s help. [*Vancouver Sun*, 4/27/11; *The Province*, 6/29/11] The second lawsuit in Quebec is being brought by Ginette Leblanc, a woman also with ALS. The 47-year-old Leblanc, like Taylor in the BC case, wants Section 241b of the Canadian Criminal Code—the section that bans assisted suicide—struck down. It’s possible that the BC and Quebec cases will ultimately be joined and then heard by the Canadian Supreme Court. [*Montreal Gazette*, 9/1/11]

- **South Australia (SA):** A bill to ultimately legalize euthanasia has generated quite a controversy of late. The bill, introduced in March 2011 by MP Steph Key, does not create a right to assisted-suicide or euthanasia like her 2010 bill that is currently stalled in the SA Parliament. Instead, the new bill creates a legal defense for doctors who act on patients’ requests to have their lives ended. Titled the “Medical Defences Bill,” the measure is so stripped of the usual euthanasia provisions that Key was able to convince more than a few fellow MPs that the bill only established legal protections for physicians in their normal practice of medicine. That, however, was before the release of official statements by Dr. Peter Sharley, president of the SA branch of the Australian Medical Association, and Ralph Bonig, president of the Law Society of SA. “This bill has enormous shortcomings... It is not fixable,” Sharley said. “It lacks protection for patients, does not prescribe a second medical opinion or written documentation from the doctor, the patient and a witness.” “A doctor could carry out treatment which effectively kills the patient with only the word of the doctor as evidence,” Sharley added.

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### ✧ You can’t take it with you ✧

Planned giving is a great way to support the Patients Rights Council. It can be as simple as leaving us a bequest in your will, or using one of the many tax-advantaged strategies available under the law. You can be assured we’ll use your gift wisely, in keeping with our mission of advocating for compassionate care for all.

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From a legal perspective, Ralph Bonig explained, "The effect of the bill is to decriminalize murder, manslaughter, assisted suicide and voluntary euthanasia in certain circumstances." Those circumstances, he said, are vague and open to interpretation. [Sydney Morning Herald, 9/14/11; The Australian, 9/17/11]

- **Britain:** According to a new report by the UK think tank Demos, one out of every 10 suicides in the UK is committed by someone with a chronic or terminal illness. The report, "The Truth about Suicide," "provides a strong argument that people with chronic and terminal illnesses should be considered a 'high risk group' for suicide" and "greater attention should be given to providing better medical, practical and psychological support to this group." [Demos, "The Truth about Suicide," 8/23/11, p. 14]

The report also noted, "Several coroners indicated that they deliberately avoid probing into suspected cases of assisted suicide, often for fear of causing problems for friends and family left behind. This means that the actual number of assisted-suicide cases in the UK is likely to be higher than official records suggest." [p. 13]

The lack of scrutiny when it comes to suspected assisted-suicide cases leaves open the possibility that homicides—made to look like suicides—or coerced suicides—where sick, elderly, or disabled victims are forced or pressured into ending their lives—are going undetected. Moreover, there have been 44 identified assisted-suicide cases submitted to the Crown Prosecution Service in the last 19 months, yet none of the people who assisted those suicides have been prosecuted. [Daily Mail, 9/6/11; Telegraph, 9/5/11] ■

The Patients Rights Council (formerly the International Task Force on Euthanasia & Assisted Suicide) is a human rights group formed to promote and defend the right of all patients to be treated with respect, dignity and compassion and to work with individuals and organizations to resist attitudes, programs and policies which threaten the lives of those who are medically vulnerable. To those ends, the PRC compiles well-documented and up-to-date information on a whole range of end-of-life issues, including health care advance directives, futile care policies, health care reform, and doctor-prescribed death.

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