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Patients Rights Council

Update

Study finds a patient's wish to hasten death may not be what it seems

A patient's expressed wish to die should not be taken at face value, according to a study recently published in the journal *PLoS ONE*.

The study, by researchers from the Universitat Internacional de Catalunya in Barcelona, Spain, found that a patient's "wish to hasten death" (WTHD) is "a phenomenon that does not necessarily imply the wish to die." Rather, the researchers concluded, "it appears as a response to an overwhelming emotional distress among patients in the advanced stages of disease."

The purpose of the study was to analyze the meaning and the motivation behind a WTHD in patients with chronic illnesses or advanced diseases. Researchers reviewed seven major

studies that explored WTHDs from the patient's perspective. All the studies were conducted in clinical or health care settings in the US, Canada, Australia, and China, and were published between 2001 and 2009. A total of 155 patients participated in the studies.

Researchers were able to identify six "themes" or factors which were directly linked to WTHDs:

- Physical/psychological/spiritual suffering;
- Loss of self, including loss of function, loss of control, and loss of meaning;
- Fear, including fear of the dying process and imminent death;
- Death seen as a way to put an end to suffering;

- WTHD seen as a "cry for help";
- WTHD seen as a desire for control or a way to regain control.

For the vast majority of patients, the WTHD was not a genuine wish to die, but a manifestation of a desire to live—just not in the patient's current, often lonely, state. Researchers called it "a cry for help in the face of suffering," a way patients could let others know about their suffering. "Behind each WTHD," researchers wrote, "one finds hidden desires for understanding and for someone to accompany them in their suffering and in the process of mourning for what has already been lost." Researchers also noted that, once patients felt "listened to" and

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Judge rules Canada's ban on assisted suicide unconstitutional

British Columbia Supreme Court Madame Justice Lynn Smith has struck down the section of Canada's Criminal Code that bans aiding, abetting, or counseling a person to commit suicide, ruling that the law is discriminatory and unconstitutional.

Smith issued her very lengthy and sweeping decision in *Carter v. Canada* on June 15, 2012. The case challenging the constitutionality of the assisted-suicide ban was brought by the British Columbia Civil Liberties Association and four other plaintiffs: Lee Carter and her husband Hollis Johnson (both helped make arrangements for Carter's mother to die at an assisted-suicide clinic in Switzerland and accompanied her there for that purpose), Dr. William Shoichet (a Canadian family physician who said he would be willing to provide suicide assistance if it were legally permitted), and Gloria Taylor (a patient with ALS—Lou Gehrig's

disease—who argued that, at some point during the course of her illness, she may wish to end her life). The defendants in the case were the attorneys general of both British Columbia (BC) and Canada.

The plaintiffs' challenge relied heavily on the argument that the assisted-suicide law violated rights guaranteed by Canada's *Charter of Rights & Freedoms*. It was not a new argument for this court. Nineteen years ago, another ALS patient, Sue Rodriguez, made the same claim before the BC Supreme Court, but she lost her case. She appealed the ruling all the way to the Supreme Court of Canada, but the high court found that the assisted-suicide ban was, in fact, constitutional and did not violate rights contained in the *Charter*.

While Smith acknowledged in her ruling that the Supreme Court of Canada's *Rodriguez*

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Final Exit Network and “exit guide” volunteers face felony charges, again

A Minnesota grand jury has issued a 17-count indictment against the national assisted-suicide advocacy group Final Exit Network (FEN) and four of its “exit guides” in connection with the 2007 suicide of Apple Valley resident Doreen Dunn, who was 57 at the time of her death. She was not terminally ill, but reportedly suffered with chronic pain, insomnia, and depression. [*Washington Post*, 5/14/12; *Sun Thisweek*, 5/17/12]

For her family, Dunn’s death had been totally unexpected. After an autopsy was done, the medical examiner erroneously

concluded that she died of coronary artery disease. Dunn’s family didn’t know her true cause of death until 2009, when the Georgia Bureau of Investigation—after examining evidence in an earlier felony case against FEN—alerted Apple Valley police that they had found references to Dunn in confiscated FEN documents and in the group’s computer database. [MN Public Radio, 5/15/12; WCCO TV, 5/15/12]

It’s against Minnesota law to encourage, advise, or assist another person to commit suicide. It is also illegal to remove

evidence from a death scene and destroy it, which is what FEN’s training manual says its exit guides should do in order to fool authorities into thinking the deceased person died of natural causes. [*Sun Thisweek*, 5/17/12]

On May 11, 2012, the Dakota County (MN) grand jury found that FEN, as a corporate entity, and four of its exit guides violated both state statutes. The exit guides charged were former FEN presidents Ted Goodwin, 65, and Jerry Dincin, 81; former FEN medical director
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Judge rules Canada’s ban on assisted suicide unconstitutional, continued from page 1

decision was a “binding authority” in the present *Carter* case, she said it was binding only in “certain aspects of the plaintiffs’ claims.” [*Carter v. Canada (Attorney General)*, 2012 BCSC 886, paragraph 12, 6/15/12. Hereafter cited with the decision’s paragraph number.] Moreover, she held that much had changed with regard to right-to-die issues since the *Rodriguez* decision, leaving aspects of the plaintiffs’ arguments open to her discretion. [942-947]

Throughout her decision, the judge embraced and embellished the plaintiffs’ claims, sometimes to the point of contradiction. For example, Smith agreed with the plaintiffs’ argument that the law prohibiting assisted suicide—a law that protects *all* individuals from having their lives cut short by outside suicidal pressures and coercion—could actually shorten a disabled person’s life and, therefore, violates that person’s right to *life*. “Ms. Taylor’s reduced lifespan,” the judge opined, “would occur if she concludes that she needs to take her own life while she is still physically able to do so, at an earlier date than she would find necessary if she could be assisted.” [17]

Moreover, Smith ruled that Taylor’s “equality rights” are also violated by the ban on suicide assistance. Her apparent rationale for this finding is that, since suicide and attempted suicide are not crimes in Canada, there exists a legitimate “suicide option”—a right—that Taylor and other individuals “who are physically unable to swallow pills or do other acts designed to end their lives are effectively precluded from...” [1011] This inequality creates a “distinction based on physical disability” that is discriminatory “because it perpetuates disadvantage.” [15]

This means that Smith’s ruling, if allowed to stand, not only legalizes the act of assisting another so that that person can prematurely end his or her life, but it also permits active euthanasia, the direct termination of another person’s life, as in the case of physically disabled individuals who are unable to kill themselves. One thing Smith neglects to consider is the state’s overriding interest in suicide prevention and the deleterious effect her ruling would have on those efforts.

For Smith, it’s the law’s “absolute prohibition against assisted suicide” that is the obstacle to Taylor having equal death rights. While the judge acknowledged that there is a “pressing and substantial” purpose behind the absolute prohibition—“to prevent vulnerable persons from being induced to commit suicide at times of weakness”—she ends up dismissing the need for a complete ban in favor of a compromise. “[A] less drastic means of achieving the legislative purpose,” she held, “would be to keep an almost-absolute prohibition in place with a stringently limited, carefully monitored system of exceptions...” That way, she wrote, “the legislation does not impair Ms. Taylor’s equality rights [*sic*] as little as possible.” [16] “Parliament could prohibit assisted death but allow for exceptions,” she said. [1233]

To that end, Smith suspended her ruling from taking effect for one year to give Parliament time to pass a new law with the exceptions and conditions Smith recommended. (But, that might not be so easy. In 2010, when Parliament last voted on a euthanasia/assisted-suicide bill, the measure was rejected by a vote of 228 to 59.) In addition, Smith gave Taylor a year-long exemption that would allow her to obtain a doctor’s help to die, if certain conditions are met. [1414-1415]

With respect to plaintiffs Lee Carter and her husband Hollis Johnson, Smith ruled that, along with Taylor, their “rights to life, liberty, and security of the person,” guaranteed by the *Charter*, are “unjustifiably” violated by the assisted-suicide law. [1] For Carter and Johnson specifically, the judge found the law violated their “rights to liberty because they are at risk of incarceration... for having helped a loved one who obtained assisted death in Switzerland.” [17] It would appear that Smith’s reasoning here would allow any number of duly-enacted laws to be struck down for infringing on a perpetrator’s right to liberty.

It is expected that the BC and Canadian governments will appeal Smith’s ruling. One issue might be whether the BC provincial court has the authority to disregard aspects of the Canadian Supreme Court’s binding *Rodriguez* ruling. ■

Doctor-prescribed suicide deaths increase dramatically in Washington State

Legal doctor-assisted suicide is definitely on the fast-track in Washington State. It took Oregon, the first state to legalize prescribed suicide, 13 years to reach a record high 71 reported deaths in 2011. Washington State took only three years—after its Death with Dignity Act was passed in 2008—to reach its record high of 70 reported assisted-suicide deaths in 2011. That is a whopping 94% increase over the number of prescribed deaths reported in 2009, the first year Washington’s law was implemented.

The number of reported deaths isn’t Washington’s only record-high, prescribed-death statistic. According to the Washington State Department of Health (WSDH)—the state agency required by law to keep track of assisted-suicide deaths and to issue a yearly statistical report—there were also a record high 103 lethal prescriptions written by 80 different doctors and dispensed by 46 different pharmacies.

Washington’s “2011 Death with Dignity Act Report” shares many similarities with Oregon’s report for the same year. (See *Update*, 2012, No. 2, p. 3.) That’s not surprising since Washington’s assisted-suicide law is modeled after Oregon’s, and both states’ reporting systems are virtually identical.

In 2011, the two states reported losing track of a significant number of patients who had received lethal drug prescriptions. Of the 103 patients for whom fatal drugs had been dispensed in Washington, 14 fell through the cracks of the state’s reporting system. The WSDH acknowledged having no idea whether 5 of those patients—who reportedly died—had ingested the drugs or had died of their underlying illnesses or other natural cause. For the remaining 9 patients, the state reported having no clue whether they were alive or dead.

Also like Oregon, Washington has a very low instance of death-requesting patients being referred for a psychological evaluation (only 5% in 2011) and extremely few lethally-prescribing doctors who are willing to be present when their patients ingest the deadly drugs (in only 3% of cases in 2011). [Washington State Department of Health, *2011 Death with Dignity Act Report*, 5/2/12]

Reported Assisted-Suicide Deaths in Washington 2009-2011

Report data supplied by lethally prescribing doctors, pharmacist reports, and death certificates.¹

Figures and percentages are those reported by the state.

Categories	Washington State			
	TOTAL	2011	2010	2009
Number of reported assisted-suicide deaths	157	70	51	36
Number of unreported assisted-suicide deaths	Unknown ¹	Unknown ¹	Unknown ¹	Unknown ¹
Number of reported lethal prescriptions written	253	103	87	63
Number of reporting doctors who wrote lethal prescriptions in a given year	? ²	80	68	53
Number of cases where the patient’s status (living or deceased & ingestion status) is reported as “unknown” by the state	41	14	21	20
Number of cases where prescribing doctor was present at the time lethal drugs were ingested	7	2 [3%]	2 [4%]	3 [8%]
Number of patients referred for psychiatric evaluation	10	5 [5%]	2 [3%]	3 [7%]
Patients’ reasons for requesting assisted suicide:³				
Loss of autonomy	183	79 [87%]	60 [90%]	44 [100%]
Inability to do enjoyable activities	179	81 [89%]	58 [87%]	40 [91%]
Loss of dignity	151	72 [79%]	43 [64%]	36 [82%]
Lost control of bodily functions	105	52 [57%]	35 [52%]	18 [41%]
Being a burden	78	49 [54%]	19 [28%]	10 [23%]
Inadequate pain control or concern about it	70	35 [38%]	24 [36%]	11 [25%]
Financial implications of treatment	8	4 [4%]	3 [4%]	1 [2%]
Complications after lethal drugs were ingested:				
Regurgitation	2	1 [1%]	0 [0%]	1 [3%]
Seizures	0	0 [0%]	0 [0%]	0 [0%]
Patient awakened	2	0 [0%]	0 [0%]	2 [5%]
Cases unknown	14	5 [7%]	4 [8%]	5 [14%]
Reported incidents of doctor non-compliance with the assisted-suicide law	Not Reported	Not Reported	Not Reported	Not Reported
Penalties imposed for non-compliance with the assisted-suicide law	Not Reported	Not Reported	Not Reported	Not Reported

Notes:

1. The Washington State Department of Health (WSDH), the agency responsible for overseeing assisted-suicide practice, has no way of knowing if data provided by prescribing doctors are accurate or complete. The Pharmacy Dispensing Report simply asks for general information (ie., patient & physician names and drugs prescribed) but contains no data on patient cases. Death certificates, by law, do not even indicate drug overdose as the true cause of death.
2. Since the WSDH reports do not identify the lethally-prescribing doctors, there is no way to determine the total number of doctors who wrote prescriptions beyond a year at a time. The same doctor could have written multiple lethal drug prescriptions for multiple patients over the time span since assisted suicide was legalized.
3. The Washington report states, “Participants may have selected more than one end of life concern. Thus the totals are greater than 100 percent.”

Source:

Washington State Department of Health, *2011 Death with Dignity Act Report*, 5/2/12. Washington’s 2009, 2010, and 2011 annual reports are available at: <http://doh.wa.gov/dwdal>.

A personal message to the citizens of Massachusetts:

My journey from death to life

By Alison Davis



I've been involved in campaigns against the legalization of euthanasia and assisted suicide in the UK for more than 25 years. My personal journey from death to life may help shed light on a Massachusetts 2012 ballot initiative that would legalize doctor-assisted suicide.

I am disabled, and people in Western countries seem to find it difficult to understand the realities of living with a disability. Some seem to believe that *of course* I want to die, while others have an artificially rosy view of disability. Both of these are simplistic, and fail to come to grips with the realities and complexities of living with a disability.

What I want to share with you is why I changed my mind from wanting to die to wanting to live. However, in order to do this, I need to first explain more about my condition, its effects, and the effects of other people in shaping both my life and my views.

I was born with spina bifida and hydrocephalus. I use a wheelchair full-time and a respirator at night. I have suffered a lot of pain throughout my life, and now need increasing doses of morphine to control the pain of trapped nerves caused by my collapsing spine, but even that doesn't always alleviate the pain. When the pain is at its worst, I can't move or think or speak.

A few years ago I experienced alarming and very frightening mental symptoms also, which turned out to be due to excessive doses of morphine. I was given a stark choice—take the extra morphine and live with the mental symptoms, or take less morphine, to prevent the mental symptoms, and accept more physical pain. I chose to prefer physical to mental pain. However, it is certainly a tough road to

cope with unending and severe physical pain, which I am told will inevitably get worse.

Between 1985 and 1995, due to a combination of tough physical and emotional circumstances, I lived through the most difficult period of my life.

In 1985 when I was at my lowest ebb ever, I made the decision that I no longer wanted to live. At that time, doctors believed that my life expectancy was very short. Over time, my desire to die became a settled wish that lasted about ten years. During the first five of those years, I attempted suicide several times.

My first “cries for help” included cutting my wrists to make them bleed, but not to threaten my life. This, of course, caused yet more physical pain, but seemed in some strange way to alleviate the unbearable mental pain that was with me night and day, maybe because it was a pain I could control. My friends went through the house removing sharp objects with which I might possibly hurt myself, and I can clearly remember, through the mental haze, eating scant meals with a spoon because all the knives had been removed.

Despite this, I continued to find ways to hurt myself, and made several very serious suicide attempts. I tried various methods: large overdoses of drugs and badly slashing my wrists with an old rusty penknife that had escaped the general removal of sharp objects. I was determined to succeed then—especially on one occasion.

I had taken a large overdose of painkillers and cut my wrists badly. I then drank a whole bottle of Martini,

lay down in bed, cuddled my favorite teddy bear, and waited to die.

Fortunately for me (at the time I thought most unfortunately) my friend Sue arrived shortly afterwards. She was able to let herself into my house, found I was losing consciousness and called the emergency services.

I was taken to the hospital and treated against my will—the doctors just waited until I lost consciousness and then treated me. If euthanasia/assisted suicide had been legal here then, I would certainly have requested it with no hesitation at all, and I would have satisfied all the supposedly “strict criteria” which apply in countries where euthanasia and assisted suicide are legal. If it had meant travelling to the “Dignitas” assisted-suicide facility in Switzerland, I know I would have done that.

If writing a Living Will (called an Advance Decision in the UK) had facilitated my death it would have been an easy thing to write one. I would have had no difficulty in finding a doctor to verify that I was of sound mind, that my life expectancy was appropriately short, and that I really did want to die.

In retrospect I think my overwhelming wish to die was probably due to a combination of feeling that I simply couldn't bear my life as it was and could see no hope for the future. My mind was still in turmoil from all the problems and difficulties, and nothing seemed to make me “feel better.” I would go to bed every night and hope that I wouldn't wake up in the morning.

My greatest piece of good fortune was that I had friends who did not

share my view that my life had no value. It took them—particularly Colin, now my caregiver and also my closest friend who has shared both my house and my life for the last 23 years—a very long time to help me decide to “give life another try.”

Those efforts and a trip to India in 1995, during which I visited a small project for disabled children, helped to turn my life around. Seeing these children, I felt motivated to do something for them, so Colin and I subsequently set up a charity for them. The night after leaving the project I said to Colin, “Do you know, I think I want to live.” It was the first time I had thought that in over ten years.

I now realise that, had euthanasia or assisted suicide been legal when I was so desperate, I would have missed what have turned out to be the best years of my life—never knowing that the future held such good times and that the doctors were wrong in thinking I didn’t have long to live.¹ This is one of the major problems with allowing suffering people the “choice” of an assisted death. It assumes that life could never get any better, and that doctors’ prognoses are always right. My life did get better, even in spite of continuing and worsening severe pain and suffering, and the doctors were totally wrong in thinking my remaining life would be short.

Over the years, I have taken part in many interviews on TV and radio. I have forgotten all but one of them. That one was on a radio station called Radio Northampton, and I remember it for two reasons. First of all, the interviewer was very rude and offensive, and was unwilling to listen to me. Secondly, I was extremely tired and didn’t communicate well what I wanted to say.

After the interview I felt very “down” and thought that all the effort had been in vain. Shortly afterwards, however, the program’s producer phoned me to apologize for what she called the “unacceptable behaviour”

of her interviewer. I was slightly placated.

Then less than twenty minutes later she phoned me again. This time she said that she had just had a call from a young man who said his name was John. He had that very day decided to take his own life, but after hearing what I had to say, he changed his mind.

This was certainly not due to any merit on my part, as I knew I had not stated my position well. But somehow this desperate young man had heard a message of hope, despite my verbal stumblings. What he heard helped him decide to give life another chance. This experience has reoccurred several times since then, though rarely so dramatically.

There seems to be a difference between the treatment of non-disabled, suicidal people, and those who are disabled.

Often all that desperate people, disabled or not, need is to be given hope. What they definitely *don’t* need is to be told they are right to feel suicidal and that they *would* be better off dead. This is simply the equivalent of seeing a person about to jump off a high bridge and giving them a push.

There seems to be a difference—one that I don’t understand—between the treatment of non-disabled, suicidal people, and those who are disabled. Non-disabled, suicidal individuals are assumed to be “wrong to want death” and get the benefit of government and privately funded “Suicide Prevention Programs” that go to great lengths to help these people want to live. There is even an annual “World Suicide Prevention Day,” but it makes no mention of helping ill and disabled people to avoid suicide.

On the contrary, suicidal, disabled people are all too often assumed to be “right to want death” and are given all possible help to achieve their goal. The dichotomy seems to be based on an assumption that a disabled life is necessarily useless, burdensome (to the disabled person, their families, and/or society) and not worth living.

Some years ago I read a booklet by a young British medical doctor, James Casson, who was dying of cancer. He titled his book “Dying: The Greatest Adventure of My Life.”² I think there is also a place for a book entitled “Living: The Greatest Adventure There Is.” My life has been full of pain and suffering, true. But it has also been one long adventure, with great highs and great lows. I think my eventual death will also be an adventure—but, for now, I’m content to wait for that particular adventure to come naturally, in its own time. ■

Notes:

¹ It is not unusual for doctors’ predictions about life expectancy to be wrong. Baroness Ilora Finlay, a hospice doctor, cites one case of a cancer patient who, after being given a terminal prognosis, asked for euthanasia, yet lived for 18 more years. See “Assisted Suicide is fine in a perfect world. We don’t live (or die) in one,” *The Times*, April 1, 2009.

² James H. Casson, *Dying: The Greatest Adventure of My Life*, Christian Medical Fellowship Publications, 1986.

Alison Davis lives in the UK and is the national coordinator of No Less Human, an organization that promotes greater understanding of the needs of disabled people and strives to educate the public about the threats to disabled individuals’ lives. She also lectures and writes on bioethical issues and has travelled worldwide in spite of her chronic, severe pain.



FEN faces felony charges, continued from p. 2

Dr. Lawrence Egbert, 83; and former case worker Roberta Massey, 66. Dincin and Egbert are alleged to have been present when Dunn used FEN's recommended suicide method: asphyxiation caused by securing a "exit hood" plastic bag filled with helium over her head.

According to FEN Advisory Board Chairman Derek Humphry, the Hemlock Society co-founder who wrote the how-to-commit-suicide manual *Final Exit*, FEN's exit guides "do not provide the means for their members to hasten their deaths..." [ERGO Press Release, 5/7/12] However, just last January—in a *Washington Post* feature article on Dr. Egbert that called him "the new public face of American assisted suicide"—Egbert revealed that he collects exit hoods that have previously been used to cause death and gives them to "future patients" to save them "the cost of buying a new one." [Washington Post, 1/19/12] As disability rights activist Stephen Drake has pointed out, if that is true, then Egbert is providing "patients" material suicide assistance, an act that would violate most state laws banning assisted suicide. [Not Dead Yet Blog, 5/15/12]

FEN attorney Robert Rivas called Minnesota's assisted-suicide law unconstitutional because it violates the group's freedom of speech rights by preventing FEN from instructing people on various ways to commit suicide. A ruling on that issue is expected later this year, but, last April, the Minnesota Court of Appeals upheld the state law and convicted ex-nurse William Melchert-Dinkel of encouraging two depressed individuals, who were participating in online chat rooms, to commit suicide. [Lakeville Patch, 5/15/12]

However, there have been two previous cases brought against FEN and its exit guides: an Arizona case involving the 2007 facilitated suicide of Jana Van Voorhis, 58, who had a long history of mental illness, and a Georgia case involving the 2008 assisted death of John Celmer, 58, who had been treated for cancer but was cancer-free when he died. In both cases, none of those indicted were found guilty of felonies. In Arizona, most pleaded guilty to lesser charges, while Egbert was found not guilty. In Georgia, charges were dismissed after the Georgia Supreme Court struck down the badly-worded assisted-suicide law. ■

Recent assisted-suicide developments by state

- **Georgia:** HB 1114—a bill that makes "knowingly and willfully" helping another person to commit suicide a felony, punishable by up to 10 years in prison—was signed into law by Gov. Nathan Deal on May 1. After the Georgia Supreme Court unanimously overturned a previous, ill-conceived assisted-suicide law last February, state lawmakers decided that they needed to pass another law, one that could withstand judicial scrutiny. The new bill had overwhelming legislative support. It quickly passed in the House by a vote of 115-53 and the Senate by a 38-11 margin.
- **Louisiana:** While Louisiana already has a criminal law banning euthanasia and assisted suicide, Rep. Alan Seabaugh felt the prohibition should also be made clear in the state's medical consent law. To that end, he authored HB 1086, a bill that prohibits designated surrogate health care decision makers from approving any procedure that could be considered euthanasia or assisted suicide, including any life-ending treatment or surgery for developmentally disabled patients or nursing home residents who are not deemed competent. Gov. Bobby Jindal signed the bill into law on June 16.
- **Massachusetts:** Prescribed suicide advocates in Massachusetts say they have more than enough voter signatures to qualify their Death with Dignity initiative for the November ballot. That's not surprising, considering their goal-driven signature gathering efforts even included circulating petitions at funerals. [NY Times, 5/29/12] Meanwhile, the disability rights group Second Thoughts filed a petition in the state's Supreme Judicial Court arguing that the initiative's ballot language is clearly misleading. On June 27, the court denied the challenge.
- **New York:** Last February, Assemblyman Eric Stevenson introduced a bill (A9360) that would have legalized Oregon-style doctor-prescribed suicide. The bill was referred to the Assembly Health Committee for consideration. On May 9, however, Stevenson withdrew the bill, after learning about assisted-suicide's inherent dangers.
- **Wisconsin:** After many failed attempts to pass assisted-suicide bills in the legislature, advocates this year targeted the Wisconsin Medical Society hoping to get the group to change its opposition stance on the issue to one of support or neutrality. Their resolution, however, was defeated by a vote of 13-5 in April. ■

Study: Patient's wish to hasten death may not be what it seems, continued from page 1

"accompanied," they often stopped requesting a hastened death.

The desire to control was also an important factor behind WTHDs. When patients felt that they no longer had any control over facets of their lives, the ability to decide when and how to die was seen by some as the last remnant of their autonomy—their "ace in the hole," so to speak. "For them," researchers found, "the sense of control comes from having a hypothetical exit plan... because at the end of the day they did not act on it." ■

The study highlights the importance of carefully assessing patients in advance stages of an illness for any manifestation of expressed or unexpressed WTHDs as well as the need to develop comprehensive care plans that include greater communication and understanding between patients and caregivers. [Monforte-Royo et al., "What Lies behind the Wish to Hasten Death? A Systematic Review and Meta-Ethnography from the Perspective of Patients," *PLoS ONE*, 5/12. The Study is available online at: <http://www.plosone.org>] ■



News briefs from home & abroad . . .

- **California:** An organ donor service operating in Northern California and Nevada has claimed the right to decide when to “pull the plug” on some patients in order to harvest their organs. One such patient is Gloria Woods, who was badly injured in a car accident last April and put on life support at UC Davis Medical Center near Sacramento. A month later, Sierra Donor Services reportedly contacted Wood’s husband and told him that, because his wife had indicated on her driver’s license that she would be an organ donor, Sierra Donor Services “had the right to make the decision to remove Gloria Woods from life support and then to harvest the organs of Gloria Woods in light of the Department of Motor Vehicle records.” In order to protect Woods, her husband and her parents have requested a restraining order to prohibit Sierra Donor Services and UC Davis Medical Center from deciding on their own to take Woods off life support. [*Examiner*, 5/8/12]

Incidentally, you won’t find Sierra Donor Services’ right-to-pull-the-plug claim on its web site. Instead, you are told, “Your medical care will not be affected by your decision to donate. When you go to the hospital for treatment, doctors focus on saving your life, not somebody else’s.” [www.gsds.org, under “Myths”]

- **Canada:** Hassan Rasouli—the 60-year-old man who, in 2010, contracted an infection after brain surgery and was subsequently diagnosed as being in a permanent vegetative state (PVS)—has proven his doctors wrong. When neurologist Richard Swartz assessed Rasouli’s condition at the end of January, he noted that it had “clearly changed.” He found that Rasouli was “consistently able to show a ‘thumbs up’” in response to verbal questions. The doctor also noted that Rasouli repeatedly showed the ability to track people and objects visually. As a result, Rasouli’s condition has since been upgraded from PVS to being in a minimally conscious state (MCS). This new diagnosis has substantiated his family’s claims that he was improving.

His wife, who was a doctor in Iran before they moved to Canada, had continually argued with his doctors at Sunnybrook Health Sciences Centre in Toronto, saying he was not PVS. Not only did they ignore her, but they went to court to force the family to agree to the removal of his ventilator so he could die quickly. The doctors consider Rasouli’s life support futile care with no hope of recovery. However, two lower courts sided with the family, ruling that the doctors needed the family’s approval to remove the ventilator. His doctors have appealed those rulings to the Supreme Court of Canada, which has agreed to hear the case. So far, the doctors have not backed down, even with Rasouli’s obvious signs of improvement. [*Globe & Mail*, 4/24/12; CBC News, 4/25/12; CTV News, 5/17/12]

- **Great Britain:** Delegates at the British Medical Association (BMA) annual conference have rejected an orchestrated attempt to change the organization’s policy on assisted suicide from opposition to “studied neutrality.” The vote came days after the *British Medical Journal* (BMJ) published an article by Healthcare Professionals for Assisted Dying Chairman Raymond Tallis and one by BMJ Editor-in-Chief Fiona Godlee, each arguing that, since assisted-suicide legalization is inevitable, the proper stance for the BMA and other professional health care groups should be one of neutrality. The pressure exerted on BMA delegates only intensified once the British popular press jumped on the neutrality bandwagon. But delegates like Baroness Iora Finlay, a professor of palliative care, said physicians should “never walk away from patients.” “Neutrality does not bring balance to the debate,” she added. “It says to Parliament we see it as an acceptable option.” The majority agreed. [*BMJ*, 6/14/12; BBC, 6/27/12; *Daily Mail*, 6/27/12]

- **The Netherlands:** A study on the wanted and unwanted effects of euthanasia and assisted-suicide drugs, conducted by the Dutch Institute for Health & Care Research (EMGO), found that, in 18% of euthanasia cases and 15% of assisted-suicide cases, there were “problems during the administration of the drugs.” The “most important problem” for doctors administering euthanasia drugs was finding a blood vessel for the lethal injection or the IV drip. Unwanted euthanasia drug side effects included (in order of

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Where There’s a Will, There’s a Way

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.

Please contact your tax advisor and attorney to learn how you can use planned giving to leave a lasting legacy to the PRC. If you then decide to proceed and would like to discuss the possibility of a planned gift with us, please contact:

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News briefs from home and abroad, continued from page 7

frequency) pain, fidgeting, euphoria, fear, difficulty breathing, nausea, dizziness, coughing, convulsions, and hallucinations. Unwanted effects caused by assisted-suicide drugs were nausea, euphoria, difficulty breathing, fidgeting, pain, coughing, dizziness, fear, and convulsions. According to EMGO, this 2011 study is the first Dutch research to review systematically death-inducing procedures and the effects of lethal drugs. [van der Wal, et al., "Wanted and unwanted effects of drugs used for the administration of euthanasia and physician-assisted suicide," 2011. Available at www.emgo.nl]

- **Switzerland:** On June 17, the Swiss canton of Vaud voted in favor of an initiative put forward by the local government that requires nursing homes and hospitals to permit assisted-suicide deaths in their facilities. The French-speaking canton is likely to become the

first jurisdiction in Switzerland to introduce a law to regulate the practice. Another proposal, offered by the assisted-suicide group Exit, was voted down because it would have given patients an unconditional right to an induced death. The government's proposal, which met with 62% approval, stipulates that two conditions must be met before an assisted-suicide can occur: the death-requesting patient must be of sound mind and have an incurable illness or injury. It would be up to the director of the nursing home or the chief physician of the hospital to decide if those conditions have been satisfied. Exit had strongly objected to those conditions. "If the law imposes an evaluation of the suicide request by a medical team," the group argued, "it is an unacceptable breach of individual liberty and a form of institutional paternalism." [Swissinfo.ch, 6/17/12] ■

The Patients Rights Council 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.

The *Update* is available to the general public; suggested minimum donation is \$25.00 [U.S.] a year. Add \$3.00 for foreign postage.

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