

### President's Letter

It seems like it has been a long time since I have written a letter to you. The Board has been very busy trying to reorient itself to an independent organization. This process seems to be taking more time than we anticipated but we are moving forward. We have devised a membership number system and you should have received your membership card by the time you receive this Beacon. It has been very rewarding to see the many donations arrive along with the membership payments. And I have received a number of positive comments on our return to the Hemlock name.

A new feature we will try to maintain in the Beacon is the "In Memoriam" column to honor members who have died. If you know of a member who has passed away, please send documentation (newspaper obituary or funeral notice) to me or to the editor. E-mail and postal addresses are in the sidebar on page 2.

Interestingly, I continue to receive many calls from people looking for the Hemlock Society. Back in 2004 when the national organization changed the name from Hemlock Society to End-of-Life Choices, the Florida board of directors decided to maintain the "Hemlock Society of Florida" listing in the phone directory, cross-referenced to End-of-Life Choices Florida. We are the only group in the country that continues to list an 800 phone number under the Hemlock name and, as a result, I receive about 30 calls a month from out-of-state callers looking for the

Hemlock Society! I continue to send information to these people even though they do not reside in Florida.

The Beacon editor, Portia Westerfield, and I have been working on a Guidebook for Forming a Hemlock Chapter. We think it will be helpful to anyone interested in organizing a local chapter. Looking ahead, we need to become organized statewide, so that hopefully in the near future we can begin working with legislators to set the groundwork for right-to-die legislation. In the Fall, we will begin training sessions for those interested in becoming chapter leaders. This will be an important beginning to educate prospective leaders on what this organization is about and the appropriate protocol for meetings. Chapter leaders must be informed about right-to-die activities throughout the world and also what we can do to support and inform our Florida members and the general public.

Another important issue is membership. We urgently need the younger generations to join and take up the cause. I have no objection to elders being members (after all, I am one of them) but the organization urgently needs the energy and conviction of younger members. Therefore I am asking each of you to talk to just one young person about right-to-die issues and encourage them to join us. I am not talking about teenagers, but the Gen-Xers, in their 30s and 40s, and baby boomers about to retire. This should be an issue with every one of them as they approach their mature years. Without them our Florida organization will probably not survive.

Yes, there is much to be done and I am counting on each of you to do your part. I know that many of you are limited in your ability to get out and do things but you certainly can make a phone call to a friend. In addition, you need to make certain that you have done your homework by completing your living will and appointing your all-important surrogate for health care.

Many of you have already departed for cooler parts of the country. I will be away from August 8 through mid-September. During this time, if you have questions, please continue to call our toll-free number. I will be checking for calls every few days.

Donna

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# Hemlock Society of Florida, Inc.

## Beacon Newsletter

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# Around the World

**AUSTRALIA** — The London Sunday Telegraph reported that retirees are taking end-of-life options into their own hands by making their own drugs. These individuals are setting up home labs to create a Nembutal-like drug. Some retirees have successfully smuggled drugs into Australia from Mexico. It seems that these people are willing to go to prison for breaking the law by their actions. One retiree stated, "I want to be in charge of my death. I want to have the same degree of choice in dying that I have in living—independence and dignity and no pain."

**CANADA** — A study between 2001 and 2003 found that 63% of the 379 palliative-care cancer patients interviewed believed that assisted death should be legalized. Interestingly, the same percentage of healthy adults also believed Canada should have legal euthanasia and physician aid-in-dying. Forty percent of the patients stated they would consider requesting physician-assisted dying if their condition deteriorated. There were 22 patients who said they would request physician aid-in-dying now, if it were legal. This study will inform the debate on physician-assisted dying. Source: *The Globe and Mail* newspaper in Canada.

**CHINA** — Li Yan, a 29-year-old woman suffering with muscular dystrophy, has asked the National People's Congress to legalize her right to die. She is confined to a wheelchair and says she does not want to be under the care of her siblings or a welfare institution when her parents die. Her parents borrowed about \$500 (three months wages) to buy their daughter a computer which she has learned to use by holding a chopstick in her mouth. She posted her request to a message board of a national television reporter. Within days, the story had spread throughout the country. Li now writes a daily message on her blog titled "No Way to Escape". The computer opened up a whole new world for her. It provided a form of expression but she also learned there was no cure for her. Her greatest fear is that her parents will die and she will be alone. Although the reporter published her story, Li's request for assisted death was never formally presented to the National People's Congress. It is interesting that in a country which enforces abortion with the "one-child policy" and where capital punishment is common and swift, the National People's Congress is not ready to join other nations that have legalized euthanasia. Li says she will continue to work toward having the right to end her life. Credit: *Los Angeles Times*

**CZECHOSLOVAKIA** — Czech citizens are interested in the legalization of euthanasia and the lower house deputy wants to open discussion in the legislature, although it does not appear to be likely at this time. Apparently the Christian Democrats are firmly against it and would outvote the other parties.

**ITALY** — When Pope John Paul II was dying he chose not to return to the hospital for life support involving a ventilator and kidney dialysis. Unfortunately, it is not possible for most Italians to reject unwanted treatment. Although the Constitution honors patient's rights, the medical community says doctors must keep patients alive.

*Continued on Page 3*

A law is currently being debated in the Senate that would allow patients to reject aggressive treatment but it isn't likely that this law will be passed in the near future. In fact, many European countries do not even have living wills.

There is a case in Italy in which a young woman was rendered comatose by an auto accident in 1992. The doctors continue to treat her aggressively. Her parents have gone to court seven times to have life support removed and have been told that "stopping treatment is against the law."

**INDIA** — The website of Cybernoon.com from Bombay, India ran an article on the Society for the Right to Die with Dignity. The organization is trying to educate the general public about end-of-life options and is battling hard to emphasize the importance of euthanasia. There will be a long, uphill struggle for the group.

**MEXICO** — It has been reported that the Mexican Association for the Right to Die with Dignity has been created. We wish them much success.

**NETHERLANDS** — A study published in January by the National Institute for Demographic Studies reported that between a quarter and half of the deaths in Europe involved medical intervention. The study was done in Belgium, Denmark, Italy, Sweden and Switzerland in 2001-02 and involved mainly the elderly.

Another study in the Netherlands reports that since the legalization of euthanasia in 2002, the number of assisted deaths has declined and seems to have stabilized. The study also stated that palliative care has greatly improved.

**UNITED STATES** — An AP-Ipsos Poll found that more than two-thirds of Americans believe that patients should be allowed to die under certain circumstances but don't agree on doctor assistance. People were asked if it should be legal for doctors to prescribe lethal drugs for terminally ill patients to end their own lives. Forty-eight percent said yes and 44% said no. Another question asked if a patient, under certain circumstances, should be allowed to die—68% said yes but 30% said everything should be done to keep the patient alive. There were other questions to the poll relating to demographics of religion, education, gender, political affiliation and place of residence. The AP-Ipsos poll also involved an online poll. On the question "Do you

think it should be legal or illegal to help terminally ill patients end their own lives by giving them a prescription for lethal drugs?" Of the nearly 37,000 responses, 79% thought it should be legal and 15% voted it should be illegal. Source: *Associated Press*

**ARIZONA & HAWAII** — Assisted Death-with-Dignity bills died in committee.

**CALIFORNIA** — The highly contested Assembly Bill 374 Compassionate Choices Act was tabled for the year when the Assembly failed to bring the bill to a vote. Supporters are hoping to proceed with it during the next legislative session. It was a great disappointment to all who had worked so diligently on it. The major foes have been the Catholic Church and the California Medical Association, although the California Association of Physicians' Groups was in favor of the bill.

**NEW YORK** — New York needs to get in step with rest of the country when it comes to care of patients unable to speak about their desired treatment. Seems there is an archaic law, followed by a court ruling from 1988, that says no one may make decisions about life-sustaining treatment for incapacitated patients, except for those patients who signed a health care proxy (appointment of a surrogate in Florida) or other evidence of their wishes, such as the living will. Without a living will, family members cannot review medical records or move the patient to a hospice. In other words, invasive and futile treatment may continue and palliative care is not given. Apparently, the Family Health Care Decisions Act has been stalemated for 15 years. According to the reviewed article, it is Governor Spitzer's challenge to convince the lawmakers this law is vital for the welfare of its residents. Source: *New York Times Editorial, May 13, 2007*

**TEXAS** — A 19-month-old child, who had a disease which slowly destroys brain functions, was being kept alive. The mother knew that the child would eventually die but wanted everything done to keep him alive because he still responded to her voice. BUT—the Texas law states that a hospital can stop life support for patients deemed medically futile 10 days after notice is given to the family. This law was passed by the Texas legislature and signed by then Governor George W. Bush. The Senate is now considering changing the law, allowing the patients' families more time before ending the life-sustaining treatment. Source: *Associated Press*

**VERMONT** — The Vermont House defeated the Patient Control at the End-of-Life bill in March of this year by a vote of 82 to 63.

# BOOK REVIEW

by Donna Klamm

## To Die Well: Your Right to Comfort, Calm, and Choice in the Last Days of Life

by Sidney Wanzer, M.D. and Joseph Glenmullen, M.D.

This book is a handbook that everyone should read. It is written in lay language (few medical or technical words are used). Drs. Wanzer and Glenmullen have put together a guidebook for everyone who is going to die! Dr. Wanzer is known nationally as an expert on issues of death and dying. He has worked for nearly four decades in internal medicine, first in private practice and later with the Harvard University Health Service. He is currently the president of Compassion and Choices of the Greater Boston Area. Dr. Glenmullen is a Clinical Instructor of Psychiatry at Harvard Medical School and is on the Staff of Harvard University Health Services.

Dr. Wanzer suggests there are turning points or signs which determine when one should shift from active treatment to comfort care. History points out that medical treatment has always been to cure the patient. There comes a time when one has a terminal illness for which there is no possibility of a cure—or even temporary improvement. At this juncture it is time to change gears and opt for comfort care. Nothing is done to cure the patient, only to make the patient comfortable—free of pain, stress, and anxiety. At this point

the patient may even request a hastened death. This topic is discussed fully toward the end of the book, although it is not a “how to” section.

Dr. Wanzer stresses throughout that it is very important to discuss your end-of-life wishes with everyone involved with your care. This includes your family, physicians, nurses, agent, and attorney. Another major point stressed is: EVERYONE over the age of 18 should complete living will and appointment of agent forms (in Florida an agent is called a surrogate), remembering the tragedies in the cases of Nancy Cruzan and Terri Schiavo.

The doctors not only describe real-life situations but also offer solutions to the problems. There is a chapter on the rights of dying patients which says you have a right to refuse any and all treatment. The doctor’s duty is to fully inform the patient, agent and family about the diagnosis, prognosis, second opinions, treatment choices, quality of life and options to ensure a peaceful death.

Other topics covered in the book include pain control, what to expect of your doctors and nurses, dealing with family and friends, and

options that have been used for hastened death. There is also a chapter that differentiates between sadness at the end of life and clinical depression. Another chapter covers decisions about dementia and Alzheimer’s and how we can prepare for these disabilities—there are options. For those with dementia or Alzheimer’s, the doctors offer an addendum to the living will, although this is not yet a legal document.

The Appendices contain a wealth of information and sample documents, which include a brief history of the Oregon Death with Dignity Act and subsequent yearly reports of physician aid-in-dying statistics. Also covered is information on the laws of Belgium, Netherlands and Switzerland, a listing of End-of-Life organizations, samples of a living will and Health Care Proxy Form. There is a proposed authorization form for ending life in a situation of irreversible and progressive cognitive decline.

I urge you to read this magnificent book. It provides many answers to real situations. It is easy reading and I hope you will put it at the top of your reading list. Check out the website at [www.todiewell.com](http://www.todiewell.com)

# KUDOS for Derek Humphry

Derek Humphry's book *Final Exit* was recently honored by the editors and book critics of *USA Today* newspaper. *Final Exit* was named one of the 25 most memorable books of the past quarter century. That's quite an honor. Congratulations to Mr. Humphry. We wish him continued success.

## A Fond Remembrance

by Marguerite Rinaldi, President  
Hemlock Society of Southwest Florida, Inc.

Last year, one of the pioneers in the right-to-die movement in Florida, Bill Berman, died. Bill had been active in many causes but nothing was dearer to his heart than the Hemlock Society. He was president of the Southwest Florida chapter for many years and, indeed, was a member of this Board at the time of his death.

I met Bill shortly after I moved to Florida in 1996. He was president of the SW Florida board at that time and immediately got me involved. I had been a member of Hemlock in Connecticut for several years but since I was working full-time I didn't become active in the Connecticut group. My passivity ended when I met Bill Berman. He got me on the Board lickety-split and I became very active.

I miss him. He not only had a ton of interests, but he read a lot and we had some great conversations together. As the years crept up on him, he began to have a number of health problems; as he said to me, "I have everything. You name the illness and I have it."

After his wife, Edie, died a year before him, I promised myself I would keep in touch with him and I did. My last memory of him is so pleasant that I never want to forget it. We went out to lunch, as we did every month or so, and this time he chose a different kind of restaurant. Normally, he opted for places like Perkins or other family-type restaurants. But not this time. This time, he wanted Caribbean food. I couldn't believe he wanted that spicy food but he did. So off we went to Bahama Breeze and he was happy as the proverbial clam.

I wish he were still here with us but I know life was not very enjoyable for him anymore and he was ready for it to end. He was not feeling terribly well and he missed Edie a lot. I will always remember him as a doer and he did a lot for the Hemlock Society of Florida. And I will always be glad I knew him which is, I'm sure, how all of his friends and relatives feel.

# Dr. Jack Kevorkian Released from Prison

by Donna Klamm

Dr. Jack Kevorkian celebrated his 79<sup>th</sup> birthday by being released from prison after serving eight years. He was convicted of second-degree murder in the death of Thomas Youk who had requested help from Dr. Kevorkian in ending his life. Mr. Youk suffered from ALS (Lou Gehrig's Disease). Since he was unable to end his own life, a lethal injection was administered by the doctor. Dr. Kevorkian videotaped the act and then sent the video to CBS where it was aired on "60 Minutes". The doctor has been paroled with restrictions and if they are not observed he will return to prison. One of the restrictions is that he does not assist anyone in hastening his/her death. He can, however, work toward passage of physician aid-in-dying legislation. We wish Dr. Jack the best in his endeavors and improved health.

# Have You Forgotten Something?

To date Hemlock Society of Florida has a membership of 180. Are you one of them? There are several right-to-die organizations to belong to but your Florida organization needs your support. Many of you have been quite generous in making donations in addition to your memberships and it is greatly appreciated. The Board of Directors of Hemlock Society of Florida deliberately made the dues reasonable so that you could be members of the Florida organization in addition to a national group.

It must be stressed that we need your support in order to continue. There are expenses to be covered in order to serve you. They include the publication of the Beacon, information that is sent to those who inquire about the Hemlock Society (this requires postage and the printing of materials sent), printing of the brochure and Advance Directive packet, and general office supplies such as postage, stationery, telephone (general phone service and directory listings). And remember—there is no paid staff. Everyone who works for Hemlock Society of Florida is a volunteer! That includes your president and the editor of this Beacon. So, just in case you forgot, please send your membership check today. Thank you.

## IN MEMORIAM

Bill Berman, Fort Myers  
Adelaide Snyder, Tallahassee

## DONORS

We would like to recognize individuals and organizations that have donated to the Hemlock Society of Florida and the Hemlock Foundation of Florida. Your financial support is critical to the operation of these organizations and is greatly appreciated. REMINDER: If you want your donation to be deductible from your income tax, your check must be made payable to the Hemlock Foundation of Florida, Inc. Your dues and donations to the Hemlock Society of Florida, Inc. are not tax deductible.

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## Hemlock Society of Florida, Inc.

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**Spring - Summer 2007**

## *Mission Statement*

*Dedicated to improving the quality of dying through education and advocacy, thereby empowering all citizens to make and carry out their own end-of-life decisions. We affirm the individual's dignity and free will throughout life, including the freedom to hasten death under certain circumstances.*

*Pass this newsletter on to your physician as well as interested friends who may want to join us.  
If you would like additional copies please send request to  
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*If you no longer wish to receive this newsletter,  
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