



## IN THIS ISSUE

• Board marks 15 years; honors Humphry	Page 6
• Is 'dignicide' final word in 'suicide' debate?	8
• Is it time for DNR to RIP?	11
• Meet incoming President Brian Ruder	12
• Who qualifies for Exit Guide support?	13
• Letter calls out C&C; Maine, N.J. pass MAiD	15

# FINDING hope IN SOMETHING HOPELESS

*By Rev. Kevin Bradley, Board Member*

I am occasionally asked to talk with Final Exit Network clients or family members who have questions about religion or spirituality. They sometimes seek help in coming to terms with their faith tradition's opposition to self-deliverance.

Usually, clients have already reconciled the apparent conflict for themselves, but a family member may be struggling to understand his or her decision and its consequences.

A few months ago, I had a conversation with a relatively young man who was planning his exit and was concerned for his mother. She was perhaps more religious than he, but was supportive of his decision and planned to be at his side every step of the way. A few months later, she called me to express her gratitude and ask me about something her son had said before his death. He told her that planning his own exit gave him hope.

That didn't make sense to her, because the whole reason for his self-deliverance was that there was no hope of recovering from his illness. *What "hope" was he talking about?*

Hope is defined on Dictionary.com

as "the feeling that what is wanted can be had." Most people who contact FEN would welcome a spontaneous recovery from their illness, but that's usually not what they're hoping for when they talk to me.

Their hope may have a religious aspect, such as the hope of an afterlife of some kind. There may be a certain amount of hope in knowing that the pain will end, or the anticipated pain will not happen, although pain relief is rarely the main reason they choose self-deliverance.

Much of life seems beyond our control, even when we are healthy. When facing an intolerable quality of life, choosing the time and manner of death gives us a sense of control. That sense of autonomy is the essence of hope.

When I was a hospice chaplain, I often advised my patients to plan their own funerals as a gift to their families. That advice was intended to prevent family members from fighting about "what Dad would have wanted."

It turned out that planning their own funerals also gave patients a renewed



Rev. Kevin Bradley

HOPE continued on page 2

# Not his ~~FINAL WORD~~



## Still speaking out: Derek details birth of North American RTD movement

*By Derek Humphry, Chair, FEN Advisory Board*

In the last FEN magazine, I was described as the “founder of the right-to-die movement.” Not quite! More accurately, I am the founder of the “modern, American right-to-die movement.”

In 1979 – when I pondered starting a campaign to make self-deliverance at life’s end a well-informed action, and also to legalize Medical Aid in Dying (MAiD) – there were already two established groups in America: Society for the Right to Die, and Concern For Dying. I sought their help but was turned away. (The CEO of the second organization wrote that she hoped I’d fail.) Both groups confined their work to promoting Advance Directives (aka Living Wills).

A few years later, they faded away, and I announced Hemlock Society USA in 1980, meeting with a mixture of support and scorn. My office was my garage in Santa Monica, and financing was the royalties of my new book, *Jean’s Way*. There was no staffing for the first three years.

### HOPE *continued from page 1*

sense of purpose, which made their last days more enjoyable for everyone involved.

Ironically, preparing for their deaths gave them a reason to live, even in their last days. They wouldn’t live longer, but they could live more intentionally – and that mattered.

I shared these reflections with the young man’s mother. She breathed a heavy sigh of relief, and then said, “That makes sense, and it sounds like him. The doctors even used that word – they said his condition was hopeless. But they didn’t know my son. I can see that by planning everything about his last days, he had a sense of purpose.

“He found hope in something hopeless.”

After lots of hesitant answers, I drew together a board of eight to form a California nonprofit organization with IRS acceptance.

This was the time of bombings of abortion clinics, Ronald Reagan came to power, and Jerry Falwell was in full cry from the far right. “You’ll be destroyed,” said the cynics, to which I replied: “I’ll be here when they’re long gone.”

### Enduring

People of good will often ask me why I’m still fighting for this hot-button cause after 40 years? The first answer is, of course, that it is a basic human liberty to have control over how one dies, if the final stages are painful and distressing.

Such a noble cause, hitherto neglected, had strong appeal to me.

Secondly, at 50 years old, I was an experienced investigative journalist and nonfiction book author, accustomed to appearing on radio and television to debate issues like race relations, police corruption, and terrorism. So, I knew what a cauldron I was getting into.

I had not intended *Jean’s Way* to be a campaigning book, but that is what it turned out to be. Published in six languages, it gave me sound credentials as someone who had “been there.”

(Although unintended as a pointer, Jean’s chosen manner of hastened death turned out to be approximately the way the death-with-dignity laws in nine U.S. states are framed.)

Being a leader of the right-to-die movement enabled me to: **1)** fight for reform in a field I sensed was coming to the fore, as were abortion rights, gay rights, and same-sex marriage; and **2)** use my background as a writer and speaker to promote this

**FINAL** *continued on next page*

# Julia Hanway – *jack of all trades, master of each*

By Janis Landis, Ex-FEN President

– Hanway is leaving FEN for other opportunities

That headline is what I found myself gratefully saying throughout my presidency. When Julia began working with FEN in 2014, I knew we had someone to fill in major gaps in our technology and databases, but I had no idea she would build our new infrastructure and outreach in a transformative way.

We had no efficient way to track and monitor membership payments. Julia developed a system that not only did that, but was robust enough to answer all kinds of queries while ensuring data protection. With wizard-like skill, she produced a newsletter that was glossy, full color, more informative – *and cost less!*

She helped us: develop a highly effective speaker program to reach groups around the country; produce



Julia Hanway

the World Federation of Right to Die Societies,” said Faye Girsh. “Advocates global-wide came together in Chicago in 2014.”

Missing from Julia’s accomplishments are the dedication, enthusiasm, and creativity she brought to her work. She was a full partner in every aspect with our volunteers, the board, and FEN leadership. There was no job she couldn’t do, no workload too heavy, no deadline too short.

Julia’s most lasting gift may be this: She lets us move forward with confidence that we have 21st-century tools to keep fighting for death with dignity.

**FINAL** *continued from prior page*

vital but contentious issue.

## **Final Exit Shock**

I had co-authored two books on the history and philosophy of euthanasia (with modest sales) but hit an unexpected controversy with my 1991 book *Final Exit*. No publisher in U.S.A. or U.K. would touch it at first, so I published it myself under Hemlock’s imprint.

Initial sales were mostly to Hemlock members, but when the *Wall Street Journal* published an article describing it as “a suicide guide,” the book instantly climbed to the #1 bestselling nonfiction hardback in America. No one was more astonished than me!

The first print edition sold 550,000 copies, earning Hemlock \$1 million net of expenses. In many bookstores, customers lined up in the morning to snatch the day’s deliveries – and Hemlock’s membership rocketed.

Book earnings enabled Hemlock to finance (to the extent permitted by law) the upcoming citizen initiatives to legalize physician-assisted dying. To assist the campaigns, Hemlock Society contributed \$1.2 million, also freely lending its mailing list.

Like Rachel Carson’s *Silent Spring* and Ralph Nader’s *Unsafe At Any Speed*, it was a breakthrough book on an emerging social issue. (I kept the paperback and eBook rights for my support.)

Cynics predicted that the suicide rate would rocket. Data showed a year later that it had not done so – plus, more suicides were less violent.

*Final Exit* still sells worldwide in updated editions after 29 years in print; up to two million copies in hardback, paperback, and Ebook. Translated into 13 languages, it is extensively pirated on the internet.

## **All on Record**

For 20 years, the Allen Library at the University of Washington in Seattle has been building America’s largest archive of right-to-die materials, including all documents, newsletters, and books from Hemlock. Keep that in mind when doing serious research.

My greatest personal reward from 40 years involved in this movement has been meeting and working with the finest, most selfless and generous bunch of Americans. I elected to immigrate here from the U.K. in 1978 (now a citizen) and have never regretted it. The darker side of America has not personally touched me, although I am keenly aware of it.

This swansong notwithstanding, I’m still helping our cause, aiming to be on the scene until my end.

© Derek Humphry 2019

*Editor’s note: Derek’s memoir, Good Life, Good Death (Skyhorse, New York, 2017) is on Amazon or (signed copy) at <https://www.finalexit.org/ergo-store>*

# FEN NOTES 15 YEARS OF HISTORY

*Editor's note: On our milestone anniversary, it's appropriate to look back at our past – to inform new members of our origins and remind long-time supporters how far we've come.*

By Faye Girsh, FEN Advisory Board

Final Exit Network is a predominately volunteer organization that provides personal support for individuals facing end-of-life suffering. It's an outgrowth of the Caring Friends program of Hemlock Society USA.

Derek Humphry started Hemlock in 1980 in Los Angeles following the success of his book, Jean's Way, which tells of helping his first wife die after she suffered a long fight with cancer. Hemlock Society grew to 40,000 members with 80 chapters and moved to Eugene, Oregon.

Hemlock always had two goals: to help people prepare for a peaceful death, and to change laws to permit aid in dying.

In 1991, Derek published his still universally successful book, *Final Exit*, the most important do-it-yourself publication of its type (now in 13 languages and its 3rd edition). He resigned as Hemlock president to continue writing and start ERGO (Euthanasia Research and Guidance Organization).

Hemlock went without a leader for a few years and moved its headquarters to Denver. In 1996, I became president. In that year, two important legal decisions occurred: Both the 2nd and 9th Circuit courts of appeal agreed that assisted dying was a constitutional right. In addition, Jack Kevorkian was telling the world why a doctor could – and should – help people who were suffering to have a good death.

Janet Adkins, a Hemlock member with Alzheimer's, was his first patient.

At Hemlock, when desperate people called for an end to their misery, they were advised to read *Final Exit*. In 1997, the U.S. Supreme Court heard arguments from the 2nd

and 9th circuits but unanimously agreed that assisted dying was NOT a constitutional right.

A similar case in Florida (argued by FEN Attorney Robert Rivas for Hemlock of Florida) was denied by the state's supreme court.

These legal setbacks were discouraging, although Oregon had started to implement its Death with Dignity law in 1997. At Hemlock, I felt that offering a book to severely ill members was not enough, as helpful as it was. Members who sought a peaceful end to their suffering needed personal, individualized support and information.

To implement this idea, we started the Caring Friends program, which trained volunteers to visit people in their homes and instruct them in peaceful methods of self-deliverance. In 1998, the first class of 28 volunteers was trained, and more were added each year. Dr. Dick MacDonald was Hemlock's medical director and compassionately oversaw the program while Lois Schaffer administered it efficiently from the Denver office.

Meanwhile, the Hemlock board had decided to

**HISTORY** continued on next page



**SUMMIT MEETING** – Faye Girsh and Derek Humphry discussed the history of the U.S. right-to-die movement in a lengthy, 2015 video.

# 21 major, end-of-life decisions

By John Abraham, FEN Member

- 1) To recognize that your days will end, and begin to plan your life on that basis – accept the reality of impending death.
- 2) To choose a physician who understands how you wish to die.
- 3) How to change, or not change, your lifestyle – the way you live: activities, habits, etc.
- 4) To do the things you have been putting off.
- 5) Whether or not to receive psychological or spiritual counseling.
- 6) To let your understanding of death intensify, and improve your present relationships.
- 7) To learn to talk more openly and comfortably about dying.
- 8) How you want to be remembered by family and friends.
- 9) Whether or not to draw up (or update) a will.
- 10) To complete advance directives (living will, etc.) so those around you will know what you want.
- 11) To name your healthcare power of attorney (advocate) who understands what you want or do not want regarding medical care.
- 12) To heal relationships that may need to be mended.
- 13) Whether or not to carry (or update) life insurance.
- 14) Whether to obtain hospice support to assist you and your family.
- 15) Whether to seek aggressive comfort care until death occurs.
- 16) Where you would like to die.
- 17) Who you want, or do not want, with you when you pass.
- 18) To continue or stop medical treatment.
- 19) To continue or stop eating and drinking.
- 20) To receive visitors or not during your treatment – determine whom they would be.
- 21) Whether or not to apply for Exit Guide assistance from Final Exit Network if you are considering to hasten your death.

## HISTORY *continued from prior page*

change the name of the organization which, in 2003, became End of Life Choices. After disposing of all things “Hemlock,” the board chose to merge with a smaller organization in Washington state, Compassion in Dying, run by Barbara Coombs Lee. The union occurred in 2004 with the new name of Compassion and Choices (C&C), which was dedicated to physician aid in dying for the terminally ill.

The Caring Friends program was never restricted to terminal patients, nor did it rely on medical means that were difficult to obtain; also, they worked with early Alzheimer’s patients. Caring Friends volunteers were just Hemlock members – not doctors, usually older, and trained to instruct patients in reliable and painless methods.

The future of Caring Friends in the new organization was unlikely to be friendly; Schaffer, MacDonald and I soon had our positions terminated. In 2004, a group of Hemlock volunteers – including Derek and I, and sparked by Ted Goodwin, a Caring

Friends volunteer, chapter leader, and national board member – met in Chicago to continue the work of Caring Friends, but calling itself Final Exit Network (FEN). We shunned fancy offices and well-paid administrators and became a virtual organization, now based in Florida but with no building. FEN teamed with NuTech, an informal technological company that discovered the inert gas method now recommended.

Compassion and Choices successfully continues its mission to change the law, while dedicated, caring, Final Exit Network “Exit Guides” go anywhere in the country to be with people, at no charge, who desperately seek a peaceful way to die, even in states where Medical Aid in Dying exists.

Both FEN and C&C are 501(c)(3) not-for-profit organizations seeking to achieve the choice of a peaceful death. FEN volunteers work on a medical model, but will work with people who are not necessarily terminal, including those suffering from early dementia.

# FEN fetes Humphry; marks anniversary

Dozens of FEN members – including those with the Exit Guide Program, board of directors, and advisory board – convened in Chicago July 25-28 to mark the group's 15th anniversary and honor Derek Humphry for his decades of work and dedication in leading the right-to-die movement.

Faye Girsh moderated a tribute to Humphry, live and via video, who watched the proceedings from his home in Oregon and spoke to those in attendance at the annual meeting.

Some who couldn't attend – including Barbara Coombs Lee, Philip Nitschke, and Dr. Richard MacDonald – sent video greetings to Humphry.

The board of directors took a number of steps:

- Vice President Brian Ruder succeeded Janis Landis as president; Ron Liesemer was named acting

vice president; and Marty Seidenfeld retired from the executive board to be on the advisory board.

- Client Services Director Lowrey Brown's job was made a full-time, paid position.

- Bill Schoolman will head the speakers' bureau.

- Approval was given to update FEN messaging, redesign the website, and adopt a strategic outreach plan.

Pointed discussion centered around acceptance criteria for the Exit Guide Program and whether psychosocial characteristics should carry more weight. No policy change was made, but the board did approve moving forward with development of a FEN Advance Directive for people with dementia.

*Editor's note: More news and detail from the annual meeting will be included in the fall issue of this magazine.*

## Provocative topics spur blogging boom

In early summer 2017, Gary Wederspahn, the FEN board member responsible for outreach, contacted Coordinator Lamar Hankins about his willingness to write for and moderate a blog for FEN.

After some discussion, the two settled on a plan, and *The Good Death Society Blog* began on August 22, 2017.

The inaugural post was an article titled, "When free speech is a crime in Minnesota." It analysed the free-speech prohibitions that have hampered, though not eliminated, FEN's work in that state.

Since then, contributors have written nearly 100 posts about a wide range of end-of-life issues – about one per week.

Discussions have included: living and dying with dementia; problems faced by ALS sufferers; designing advance directives to get a desired death; making funeral arrangements without being exploited; answering right-to-die critics; words to use when discussing death with dignity; and a host of other end-of-life topics.

### BLOG BY THE NUMBERS

- ❑ 22,807 – Views from August 2017 through July 2019
- ❑ 1,546 – Average monthly views, June 2018 through June 2019
- ❑ 641 – Highest weekly views in past year June 24-30
- ❑ 2,195 – Highest monthly views, June 2018 (2,000 this June)\*
- ❑ 55 – Average views per day this year (was 49 in 2018)
- ❑ Highest views per day in July 2019 (all but one on Monday)
  - July 1 – 160      July 18 – 148
  - July 8 – 148      July 22 – 140
  - July 15 – 138
- ❑ 783 – Most views in one day, June 19, 2018\*\*

\* Fewest views are in November and December

\*\* Followed e-blast from FEN national office

"Our main purpose is to publish material on death-and-dying issues, and to discuss the widest range of end-of-life challenges and choices," said Hankins.

"Our objectives include creating broader public awareness, and discussion of critical issues through reading, commenting on, and sharing blog posts."

Hankins also said he and Wederspahn hope to: Position FEN as a leading resource in the right-to-die movement; link blog readers to FEN's website and other outreach platforms; and develop archives of reference/source materials for speakers and writers.

The Good Death Society Blog

A Project of the Final Exit Network

# FINAL EXIT NETWORK

## BOARD OF DIRECTORS

Brian Ruder, MS, President  
Ronald Liesemer, PhD, Acting VP  
Judy Snyderman, MBA, Treasurer  
Kevin Bradley, MDiv  
Janis Landis, MA  
Cameron Linen, MTS, MS  
Tom Tuxill, MD  
Gary Wederspahn, MA

## ADVISORY BOARD

Linda J. Banez  
Huck DeVenzio  
Ruth von Fuchs, MA  
Faye Girsh, EdD  
Derek Humphry, Chair  
Richard MacDonald, MD  
Martin Seidenfeld, PhD  
Wendell Stephenson, PhD  
President Emeritus  
Lee Vizer, MA

## EXECUTIVE DIRECTOR

Mary Ewert, PhD

## QUARTERLY MAGAZINE

Jay Niver, MA

### VISION

That any competent person  
unbearably suffering  
an intractable  
medical condition  
has the option  
to die legally  
and peacefully.

### MISSION

To educate qualified  
individuals in practical,  
peaceful ways  
to end their lives,  
offer a compassionate  
bedside presence  
and defend  
their right to choose.

# Are you 'linked in' like FEN is?

By Kevin Bradley, Board Member

LinkedIn is the premier online networking tool for professionals around the world.

I've had a LinkedIn profile for years, but it never occurred to me that it might be useful to an organization run mostly by volunteers. Then I inherited board responsibilities involved with a pilot program to see what, if any, benefits LinkedIn might have for FEN.

I was in for a pleasant surprise.

I didn't have to do much other than organize our first official meeting, because volunteers extraordinaire Christopher Sorkin and Kristin Jochum had already done the lion's share of work: FEN's LinkedIn page was up and running.

Christopher made a few tweaks and has been actively managing the page ever since.

In less than a week, Kristin used LinkedIn to find Steve Gleason, a FileMaker Pro expert who supports FEN's mission and lives in the Chicago area. He is now working with Mary Ewert,

our new executive director.

It was a real-world success story of how FEN can use LinkedIn to quickly find someone with specific skills.

*Now we need your help.*

We would like to use LinkedIn to find well-qualified volunteers for key positions and to find speaking opportunities.

1) If you're on LinkedIn, "follow" FEN's profile page.

2) If you don't want to be on LinkedIn, you can still help by finding out if any community, group, or organization you're involved with has a LinkedIn profile, and then ask the administrator to "follow" us.

3) We'll take it from there. If you're ambitious, be proactive to see if those groups might want a FEN speaker to present on the right to die (in general), or on Final Exit Network in particular.

Be sure to let them know: There is never a fee for any FEN services.

This project actually inspired me to update my LinkedIn profile and explore other networking opportunities. *Care to join me?*

# LinkedIn



# Aid in Dying Physician Assisted Death DIG AUTHENASIA Euthanasia Deliberate Life Completion Death With Dignity SUICIDE What's in

By Jerry Metz, MD, FEN Member

**W**e don't commit generosity or love. We do commit the ABCs of evil: Adultery, Burglary, Crime.

When we say someone committed *suicide*, we add that term to a list of ugly things, and we see what ponderous freight one word can carry.

Here's another word that makes heads spin, when your lovely, 14-year-old daughter says, "Mom, I'm *pregnant*."

You realize you had no idea what's up in her life, and a cosmic dump truck has plopped a large load in the middle of your world.

One word can carry enormous import, and *suicide* is that kind of word.

There are three good reasons to oppose the use of "suicide" in the context of the essential service FEN provides.

1) The word implies mental illness. If we believe life is good, then surely the rejection of it must be crazy!

2) The presumably misguided ending is a tragedy that has cut short a creative, productive life. It's a loss to society, and we grieve the loss.

3) Finally, suicide makes tongues wag and sprays a stain on the entire family – "They didn't understand her," or, "They didn't love him enough."

All three conclusions are inappropriate in our situation:

- If a tormented terminally ill patient were to say, "Every day my condition is worse. I wonder what might fail next. This is fun!" they would clearly be mentally ill.

- Our generally geriatric crowd has already given society gifts of creativity and has nothing more to give.

- Finally, as we know so well, the family of someone who exits is not ashamed, but proudly honors the patient's courage and determination.

The Bible says, "By their fruits shall ye know them" (Mat. 7:16), and many times the fruit of suicide is bitter, even poisonous, often enough to make the phrase "rational suicide" seem an oxymoron.

FEN people know better, but we have been slow to come up with a substitute for that loaded word, "suicide," and we are accused of using euphemisms.

A euphemism cloaks an ugly concept with a clever disguise that makes it socially acceptable. "My patient took early retirement," is a euphemism.

"Medical Aid in Dying" is not a euphemism because it is clear, direct, and unequivocal.

Let us commit to using MAiD.

## Asian youth

*The debate over terminally ill movement has never been more intense. The use of the term "suicide" is being avoided as advocates push to avoid being accused of resorting to transgression.*

*Derek Humphry has written about it in his ERGO Listserve. Hankins is doing the same in the Society blog.*

*Humphry is one of the few people who is terribly upset at calling "a suicide" an illustrious journalism career. He is more tolerant of candid, unvarnished truth.*

*I learned long ago how to handle this. I had talked with my young daughter after my father took his life. She was doing so. It was a couple of years later she confessed, "I didn't understand what I had to do with Gandpa's death."*

# suicide Self-Controlled Death MAiD Hastened Death Socraticide Assisted Suicide Self-Deliverance

## Is it a name?

– William Shakespeare

### movement?

ology in the right-to-die  
 more spirited. Almost any  
 becoming unacceptable  
 it – and sometimes are  
 sparent euphemisms.  
 tten and moderated much  
 rve forum, and Lamar  
 n FEN's Good Death  
 ew who doesn't seem  
 spade a spade." His  
 r might explain why he's  
 varnished verbiage.  
 terms can be confusing. I  
 daughter about euthanasia  
 to prevent cancer from  
 years later that she  
 and what 'youth in Asia'  
 ath."

– Jay Niver, Editor

### Is 'Dignicide' the answer?

By Huck DeVenzio, FEN member

Last issue, with an essay from Derek Humphry, we solicited your opinions on an alternative term that does not have negative connotations or effects.

Contrary to Juliet's assertion that "a rose by any name would smell as sweet," the right-to-die movement has long been searching for a term to replace *suicide* to describe a planned, peaceful end to suffering.

This is motivated by practical and compassionate elements.

"Suicide" carries some heavy emotional baggage in western culture: It suggests violence, mental illness, and unwillingness to continue living. That's the opposite of a quiet, rational death surrounded by friends for a person who would prefer to go on with life.

But there are also pragmatic benefits to an alternative term. The societal stigma associated with suicide can have a great impact on survivors, and may

even affect insurance claims and religious status.

When Gallup surveyed people in 2013 about the propriety of physician assistance in dying, 51 percent approved a question that mentioned suicide, while a nearly identical question without that word drew 70 percent approval.

Perceptions influence response.

Over the years, there has been a thesaurus of replacement candidates including *exit*, *patient-directed death*, *life conclusion*, *deliberate death*, *rational suicide*, *peaceful passing*, *self-euthanasia* and others.

Several had virtuous points, but none seemed to be snappy, brief, clearly understood, and positive.

Beginning in 2014, there was a global effort. U.S. attorney and activist Bill Simmons said, "I headed an international group of right-to-die leaders trying to find an alternative to suicide. We worked via internet over a period of many months. We started with a long list and cut it down."

"We couldn't find a one-word substitute, which some of us wanted," Simmons lamented.

Then one of the members dreamed up an apt word: *dignicide*. It has yet to catch on, but Simmons remains optimistic: "I think we could change the world. The right-to-die movement needs it."

Let's hear your thoughts. Send them to FEN's quarterly magazine ([www.finalexitnetwork.org](http://www.finalexitnetwork.org)), to the FEN Facebook page ([www.facebook.com/groups/finalexitnetwork/](http://www.facebook.com/groups/finalexitnetwork/)), or add comments at the end of articles on the The Good Death Society Blog ([www.thegooddeathsocietyblog.net/](http://www.thegooddeathsocietyblog.net/)).

## Good Endings Book Club



### Physician-Assisted Death

by L. W. Sumner

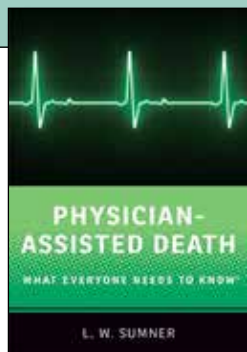
Reviewed by Huck DeVenzio

This worthy book presents arguments both for and against Medical Aid in Dying (MAiD), though Sumner uses the older terminology, Physician-Assisted Death (PAD). It looks from a variety of viewpoints, giving bipartisan coverage but ending up clearly in favor of suicide as a means of relieving suffering.

The author is a Canadian philosopher, ethicist, and author. He says his book is “a leaner, stripped-down version of my earlier book, *Assisted Death*.” If true, the earlier work must be very detailed, because one-quarter of the newer volume is notes, bibliography, and the complete 1994 Oregon Death With Dignity Act as amended in 1997.

The book is subtitled, “What Everyone Needs to Know.” In addition to political considerations, the book addresses common diagnoses of subjects (“Cancer is the overwhelmingly most frequent [nearly 80%]...”) and reasons for MAiD (“Of the 28 possible reasons, current physical symptoms such as pain ranked quite low...”).

Sumner seems particularly irked by religions that want to impose their beliefs on others, writing, “In a religiously pluralistic society, public policy governing the conduct of all cannot be justified by reference to faith-based premises shared only by some: to violate this constraint is to violate freedom of conscience. And not just freedom of religious freedom.”



## The Future of Assisted Suicide and Euthanasia

by Neil M. Gorsuch

Reviewed by Huck DeVenzio

At the author’s Supreme Court confirmation hearings, this writing attracted a lot of attention. It was held up by both sides as emblematic of candidate Gorsuch’s thinking.

It’s well-written, intelligent, and scholarly researched in legal detail, as you might expect from a prominent jurist. Perhaps this review were better written by FEN counsel Robert Rivas, but let’s save him for a future clash with Justice Gorsuch.

The initial chapters deal with historical precedents. But does it matter what Greek thinkers wrote during the Punic Wars, more than 2,000 years before the first dialysis machine?

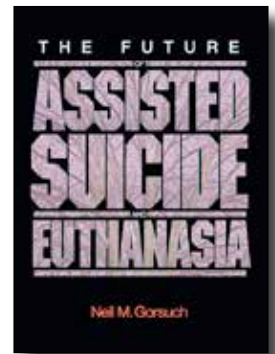
The author scrutinizes legal minutiae, dissects something called a perfectionist view of autonomy, examines the harm principle, and rigorously explores substantive due process – but he seems to lack heart.

The book doesn’t get to the crucial question: *What is the right thing to do? What’s best for your suffering mother? Is it okay to impose your values on someone of a different religion or beliefs?*

The author makes some strong points, but where’s the humanity? The care that anti-choicers express in protecting the poor and the disabled from abusive outcomes (the slippery slope argument) appears as paternalism: I’ll look out for you since you are too poor or disabled to do so for yourself. Give me freedom to choose, not paternalism.

The Bible, which is credited with weighing in on just about every topic, is apparently mum in this case (“... the Bible nowhere explicitly forbids suicide”). Nor does Gorsuch acknowledge the influence of religious dogma in this debate.

And some of his views would have to be softened now that 10 U.S. jurisdictions permit Medical Aid in Dying, and more medical and legal associations have gone neutral, as opposed to just Oregon having legal MAiD when he started writing the book.



# IS IT TIME FOR DNR TO RIP

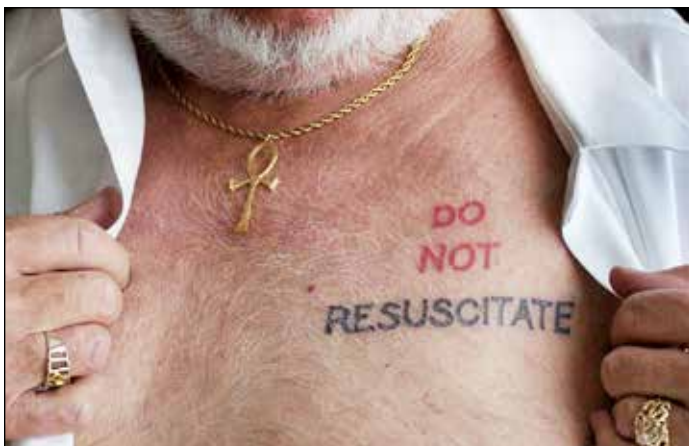
*By Amber Barnato  
and Maxwell Vergo*

**T**he term DNR (Do Not Resuscitate) means that a patient should not receive cardiopulmonary resuscitation (CPR) in the event of cardiopulmonary arrest (i.e., when the patient has died; is unresponsive, has no pulse, and is not breathing).

But many patients and healthcare providers misinterpret a DNR order to mean that no life support should be given in the event of clinical deterioration (i.e., the patient has not yet died but is getting much sicker).

Efforts to change the terminology to “do not attempt resuscitation” or “allow natural death” try to solve some of the misunderstandings, but only confuse people further. The added “attempt” is inserted in the former to remind us that CPR is usually not successful. “Allow natural death” seeks to remind us that the procedure is applied when someone has already died.

A more obvious solution would be to name it what it means: no CPR.



**WISHFUL THINKING** – Despite the supposed clarity of a DNR tattoo, conflicts can arise in a facility or hospital where medical orders must be initiated and signed by the attending physician.

The ability to designate a preference against CPR is critical for patient autonomy. Eliminating the term DNR and replacing it with “no CPR” would make it more transparent to patients, families and providers what, exactly, is being withheld.

While this change will be burdensome for the state governments, hospitals and nursing homes that would need to modify policies, forms and information technology, healthcare systems make changes all the time for even less compelling reasons. For example, the U.S. recently adopted a brand-new diagnosis and treatment code categorization system to improve billing detail, estimated to cost more than \$1 billion.

So, to reduce confusion and medical errors, “DNR” is a term that should be laid to rest.

*– Excerpted from The Hill [Washington, DC], May 5, 2019*



*“You call this ‘death with dignity’?”*

# Arriving Words

*By Brian Ruder*  
*FEN Board President*

First, I want to thank Janis, the FEN Board of Directors, and other FEN leaders for creating the strong organization we have today.

- Because of your continued support, FEN is in good financial shape.
- New Executive Director Mary Ewert brings a history of experience and activism.
- Our Guide Program is in excellent shape thanks to experienced leaders, coordinators and guides.
- And we have a very capable board that is moving FEN forward in a number of areas, including research and outreach.

As your new president, I want to assure you that my primary goal is to build on the organization we have today. As we continue the transition to a more traditional executive director-led organization, I have two primary goals for our organization: The first is to continue to make the organization as sustainable as possible; the second is to continue to improve our communications to members and non-members.

To make our organization more sustainable, we will focus on managing costs very carefully. I understand that we must be good stewards of our funds and be responsible to you for how we spend the money you provide.

The other aspect of sustainability is to make sure we have an organization that can provide our services over time. This includes ensuring that we have sufficient trained guides and staff to



meet client and organizational needs – *and it means trying to continue to lower our organizational risks.*

In my years working in the corporate world, I found that good communication is one of the keys to a successful organization. Over the next year, we will be reviewing all our messaging to make sure we are clearly communicating our value proposition and goals to members and supporters.

We want people to know what we are doing to provide

more options and opportunities for managing their end of days. We hope to provide more newsletter articles from our volunteers about their experiences and work efforts, in addition to stories from members and supporters.

To improve communication with prospective members, we will be upgrading the FEN website to make it consistent with our existing vision, mission, and goals. We also hope to make it easier for members to renew their membership and make donations, as a way to reduce our costs of membership and processing donations.

You'll hear more in coming months.

Finally, we will continue to focus on providing compassionate education and support to eligible people interested in using our services.

---

*Brian succeeded Janis Landis as board president at the FEN general meeting July 26 in Chicago. He has been a Senior Guide and board member since 2017 and lives in Portland, OR.*

# Guiding to the exit

## *The Exit Guide Program – what's required of applicants*

**O**n a plane, “exit guides” would be travelers seated nearest to the emergency doors. In Final Exit Network, an Exit Guide plays a vital, intimate role in peoples’ lives – and deaths.

Nothing is more central to FEN than the Exit Guide Program. “It’s the heart of what we do,” said Client Services Director Lowrey Brown. “We field a lot of questions about how it works.”

She noted how important it is for FEN members and the public to know whom FEN serves and how to apply for the Exit Guide Program.

❑ The time to apply for Exit Guide support is within a year of wanting to self-deliver. “We encourage everyone to plan ahead and consider difficult decisions before being faced with them,” Brown said, “and our coordinators will happily steer those looking ahead toward resources for doing so.”

❑ When someone inquires about Guide services, the message is forwarded to a coordinator – an end-of-life expert who counsels on more than just the program. “They work with callers to see if they might be eligible for Guide support,” Brown explained. “If so, they shepherd applicants through the process.”

❑ FEN membership is not required to apply for the program; it also no guarantee of being accepted.

❑ The Exit Guide Program serves competent adults who consider a life-ending decision and are able to self-deliver without assistance. They must communicate with family and loved ones about the choice they’re considering, and those individuals

must, at the very least, respect their eventual decision.

❑ Applicants must have at least one medical issue that severely reduces their quality of life – but they need not be terminally ill or within six months of death. They must meet at least one of these criteria:

1) Serious disease – like cancer, multiple sclerosis, cardiopulmonary or other organ-related problems;

2) Chronic, severe, somatic pain – ailments more difficult to diagnose, such as complex regional pain syndrome and fibromyalgia;

3) Loss of selfhood through dementia – those who wish to hasten their death while still competent;

4) A constellation of conditions that significantly diminishes life’s quality – typically age-related, but including chronic maladies like diabetes.

Guide support for those who primarily have mental-health diagnoses are not currently eligible.

❑ Working with coordinators, applicants submit a statement about their condition and how it impacts them, along with medical records of support. When coordinators receive the paperwork, they schedule an interview that gives a bigger picture of circumstances.

❑ The Medical Evaluation Committee reviews the application to ensure it falls within one of the required categories. If so, it is accepted for assignment, and a Guide is appointed to the client.

“Our process is one of continual evaluation,” Brown said. “Being assigned an Exit Guide is only the first step, and FEN Guides are always reassessing every situation.”

# New editor lost 2 loved ones in opposite ways

Jay Niver, the new FEN quarterly magazine editor, is a recently retired journalist and public-relations consultant who became involved in the right-to-die movement by supporting and documenting his father's "final exit."

Sam Niver had terminal prostate cancer in 1998 and was determined to make a statement about death with dignity. He asked two of his physicians for prescriptions for Nembutal, which gave him all he needed for a front-porch demise overlooking a coastal bay in North Carolina.

The state has no law against assisted suicide, so Jay and twin sister Gretchen were with Sam to help and support him. The *Raleigh News & Observer* published a Sunday, front-page feature story on Sam's choice, and his children produced an award-winning documentary film about his life and death.

An Ohio native, Jay worked 30 years in the Carolinas before moving to Canada and returning after his wife's drawn-out surrender to terminal disease. He has extensive experience in corporate and healthcare communications, as well as editing newspapers and specialized publications.



**FATAL DOSE** – Sam Niver drinks a Nembutal concoction in 1998, to die peacefully before his metastasized prostate cancer can kill him. A suicide note is pinned to his shirt.



**DRAMATIC DECLINE** – Editor Jay Niver and his wife, Lee Anne, are pictured in the inset photo taken in October 2016. The other photo shows her 13 months later, at half her weight, after 22 weeks in hospital and hospice care.

Niver earned a B.S. in Journalism from Northwestern University and an M.A. in Teaching from The Citadel in Charleston, SC. He worked years for The Cleveland Clinic, Medical University of South Carolina, and AMI East Cooper (SC) Hospital. As a freelance consultant, he addressed issues including at-risk youth, addictions, domestic violence, and public housing.

His late wife, Lee Anne Hanson-Niver, suffered from idiopathic pulmonary fibrosis, a progressive, debilitating disease that impacted her last years of life; Niver quit work to provide full-time care.

"We went to the E.R. on May 29; we were in the hospital or hospice all but two nights until she died in November," Niver said. "We lived in Canada – we could have had Medical Aid in Dying. She relied instead upon her evangelical faith.

"I've seen both ends of the spectrum: my father, who was proactive, and my wife, who couldn't accept the inevitable."

Niver said he's flattered to assume FEN newsletter duties. "I've got big shoes to fill after all Huck (DeVenzio) did with the magazine. I hope to continue the direction he and the board were taking with the publication," he added.

"FEN is built upon volunteers and dedicated to its clients. I hope we can continue to share their stories and laud the work of our Exit Guides."

"FEN has found a well-qualified person," said DeVenzio, the former editor. "He's an accomplished writer and editor who has seen first-hand both a peaceful exit and a tragic demise."

## Two decades is long enough to exclude so many

*FEN Senior Medical Advisor Dr. Richard MacDonald, former Hemlock Society medical director, recently sent the following letter to Compassion & Choices in response to their appeal for contributions. He had not received a reply by the time this publication went to press.*

I, and many others who have been involved in the effort to provide choice near the end of life, have become dissatisfied with C&C leadership.

Many of us have been truly active since the 1990s and before. The reasons I will no longer support C&C are important ones ...

It has become evident that C&C will not change the type of law they promote in state after state, and that law is not a progressive one.

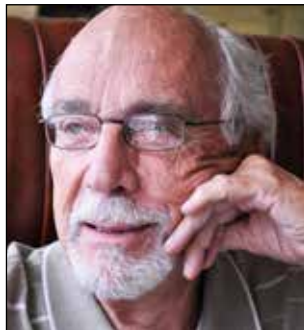
Insisting that no changes be made for the benefit of those who are dying and looking for a peaceful, sure, and timely dying process is regressive. And that is what C&C leadership has shown by opposing the suggested important modifications of the Oregon law, which fails to include those patients with the most lingering, quality-of-life-destroying symptoms.

I refer especially to degenerative neurological conditions that will not be covered by the older law. Sadly, laws like Oregon's original one are being insisted upon in states that pursue legislation. And, incredibly, C&C leaders are urging opposition to modifications, putting them in alliance with pro-life groups, Not Dead Yet, and the Catholic Church.

I would hope that some influential C&C board members – and staff who are in important, paid positions – will urge a change in the regressive actions of C&C leadership.

Patients suffering from ALS, MS, Parkinson's and other neurological conditions – including dementia – are hoping for compassionate changes to existing laws and passage of more-progressive, new ones.

They, too, have a right to a peaceful dying process when they decide their quality of life demands it.



**Dr. Richard MacDonald**

## Maine, N.J. approve MAiD

In a rare, relative flurry of success, two more states – New Jersey and Maine – passed laws to allow Medical Aid in Dying (MAiD) between April and June.

That brings to 10 the number of U.S. jurisdictions where MAiD is permitted. Ironically, it's in the shadow of a bombastic, "pro-life" president – inspiring right-wing legislatures across the country – that more states are moving toward "death with dignity."

In 20 years between Oregon's groundbreaking law and Donald Trump's election, three states enacted MAiD legislation (Washington, Vermont and California). Less than three years since Trump was voted president, four states and the District of Columbia have done so.

Proposed legislation was debated but defeated this year in a number of states, and the Connecticut State Medical Society voted in favor of "engaged neutrality" after years of opposition.

The U.S. population is getting older with less tolerance for suffering – but there's still been no accommodation for patients with slow-progression diseases like ALS or Alzheimer's (see letter at left). In that Oregon, Bruce Yelle and End Choices fought hard to make MAiD available to people with irreversible illness, even if death wasn't imminent.

He had modest success: eliminating the required 15-day waiting period for patients who meet all requirements for MAiD, but who might die short of that time.

## Better self-deliverance info

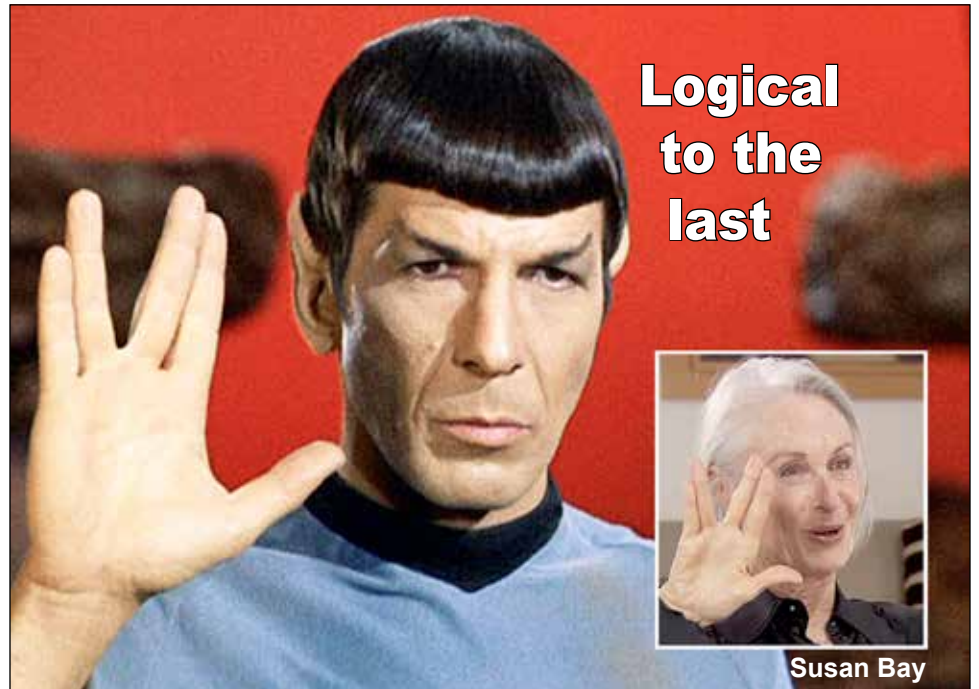
ERGO (Euthanasia Research & Guidance Organization) has updated and improved its top-selling e-document, *How To Make Your Own Inert Gas Hood Kit*, by Derek Humphry.

This is good news since there is no longer anywhere a constructed hood kit can be obtained.

It is available only from the nonprofit, ERGO Bookstore (<http://www.finalexit.org/ergo-store/>), as a digital download PDF. It is clearer and better illustrated, but if you already own the prior document, the newer version does not contain any revelations.

This DIY manual is to be considered by competent adults with terminal or degenerative illness.

FINAL EXIT NETWORK  
P.O. BOX 10071  
TALLAHASSEE, FL 32302



## Widow: Nimoy wanted end to suffering

In February 2015, the actor known for playing Star Trek's iconic Mr. Spock died of complications from chronic obstructive pulmonary disease (COPD), brought on by years of heavy smoking.

Leonard Nimoy spent a substantial part of his final years campaigning against smoking. But, according to his widow, Susan Bay, in a May interview with *Inside Edition*, he may have also held other beliefs that appeared in his waning days.

She said Nimoy asked his nurses to end his life.

"Leonard believed in dying with dignity. He didn't want to be confined to a wheelchair and not able to breathe," she recounted.

Apparently, his caregivers added more morphine to his medication, relieving the discomfort and possibly hastening his death. As his fictional character might say, "It's only logical."

