Final Exit
NETWORK

The Human Right To A Death With Dignity

In This Issue

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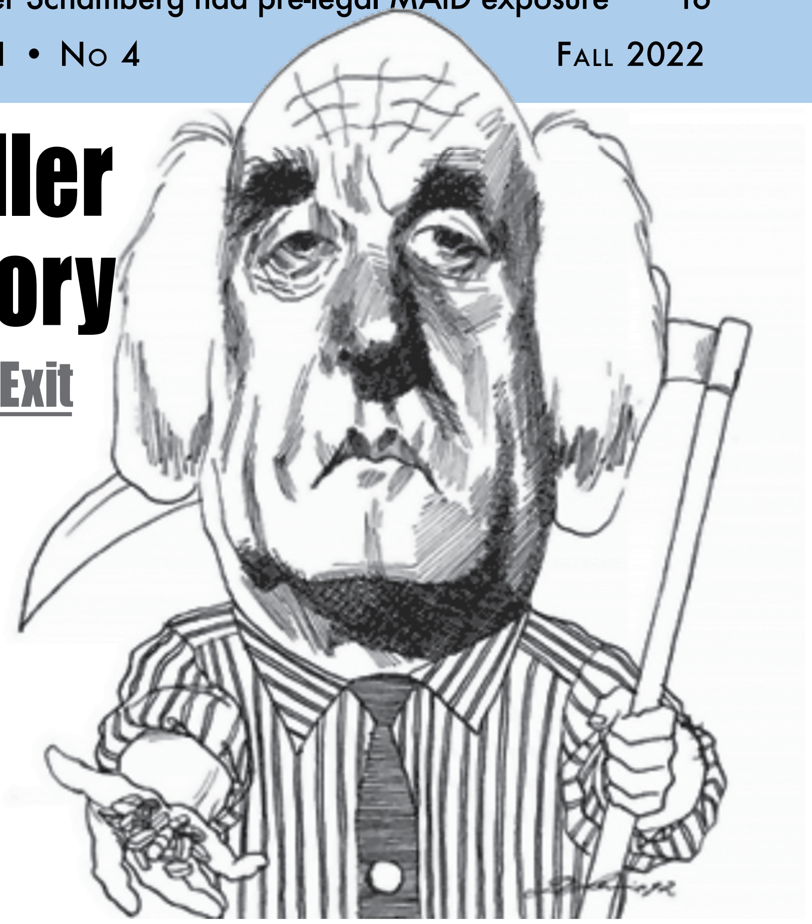
An unlikely best seller had a rocky backstory

The controversial history of Final Exit

By Derek Humphry, FEN Co-founder



One of the strangest stories in book publishing is that of Final Exit, which, after a bumpy 31 years, still sells 24/7. It has been condemned, admired, banned, and also a #1 *New York Times* best seller.

Sometimes called "the ultimate how-to book" or "the suicide book," there have been 11 translations. It is in most libraries.

Yet the birth of this book in 1991 was a lopsided saga. My previous DIY book, Let Me Die Before I Wake, had been selling steadily for a decade by the old Hemlock Society (1980-2004), but by now the issue of choice in dying at life's end had become more accessible, thanks in part to Dr. Jack Kevorkian (1928-2011), who famously helped 130 people to die.

When written, Final Exit was offered by literary agents in New York and London to publishers without any response. One UK editor noted that she turned it down, but when she got home that evening, she found her father reading the original Hemlock version.

So, I decided to publish it myself. A contract was drawn up apportioning the hard-cover rights to Hemlock and all other rights to me. I printed 30,000 copies: I knew that most of the 40,000 Hemlock members would want it.

Over the next six months, I mailed 200 review copies to newspapers and magazines, but nobody even mentioned it. We had a national distributor, yet the book sat in bookstores gathering dust for months. It seemed I would have to rely on my membership audience.

Then, when I was on holiday in England, a call came from a reporter on the *Wall Street Journal* who said she'd been told by her editor to interview me about the book, which he'd heard interesting talk about at last night's dinner table.

On July 12, 1991, a thoughtful, balanced article by Meg Cox appeared, prominently leading the newspaper's Friday marketplace section. She quoted people who liked the book and said who would hate it.

By Monday, the copies languishing in bookstores were all sold. The distributor called and asked me for 100,000 more – and he kept on repeating this order.

By Aug. 11, it had shot to #1 of the *New York Times* best-seller lists and remained there for 18 weeks. Customers were frequently lining up in bookstores to get that week's delivery.

Hardly anyone reviewed it, but cynical news

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FINAL EXIT

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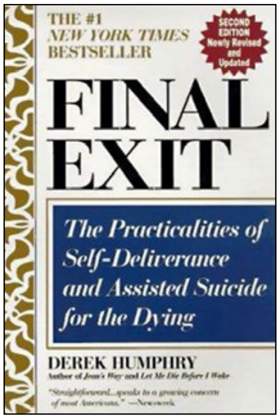
columns about this scandalous “suicide manual” were numerous. One columnist opined that “only in New York would people take a number and line up to get a how-to book on suicide.”

The more it was condemned, the more people bought it who were not afraid to think about death.

For a month, I spent almost full time on TV, radio, and in print media interviews. *Time* and *Newsweek* devoted whole pages to it. At many dinner tables, the conversation centered on what negatively might be happening to America that such an unusual book could be so popular?

Its enemies made dire media predictions that the book would escalate the overall suicide rate. But official statistics later showed that the rate had not gone up, although there were more suicides using the plastic bag technique.

The Roman Catholic Church deemed it “a new low in publishing.” The Right to Life Committee called it “a loaded gun.” Canadian newspapers demanded it should not cross the border – which it then did in huge quantities. In contrast, the world’s most prestigious scientific journal, *Nature,* welcomed it on its front page as necessary for its time.



Cartoonists had a field day lampooning the book. I have a collection of 16 syndicated drawings, most rather corny, except the humorous one by David Levine (P-1) accompanying an analytic article in the *New York Review of Books*.

Those who noted the book’s subtitle, “The Practicalities of Self-Deliverance and Assisted Suicide for the Dying,” and took the trouble to read it saw its value. Fundamentally, the book is a vital briefing on death and dying for people who had not so far addressed it.

Many buyers opined that they had observed the awful dying of their parents and were looking for alternatives for themselves.

After the first year, the Hemlock Society said the book had earned it $1.1 million after expenses (money spent on legislative advocacy). And it was consistently selling. I sold the paperback rights to Dell/Random House and the translation rights in 11 languages.

When a French version arrived in Paris, somebody complained that such a book was against the law. So, it was banned, but when the police went to seize copies, the publisher was tipped off, loaded the entire stock on a truck, and shipped it to Belgium.

Final Exit was instantly banned in Australia. After we appealed, it was permitted in book stores, provided it was shrink-wrapped and kept on a high shelf (like girlie magazines once were).

Libraries complained that they had to keep buying more copies because of the abnormally low rate of customer return.

Still, today the book consistently comes in on Amazon’s sales chart at between 20,000 and 40,000. It sells on KINDLE and audio books. The eBook version, Final Exit 2020, is most popular.

Showing how widely the English language is spoken, ERGO’s Internet bookstore is accessed by customers in Australia, Japan, Finland, and Hungary, to name a few.

With all the translations, Amazon sales, and eBooks over 31 years, it is difficult to put a figure on how many total copies have actually sold. (The book was hugely stolen in pirated versions.) It’s likely to be at least 2 million books.

Final Exit got an inadvertent boost when it was mentioned in the Oscar-winning film *Nomadland*.

In that 2020 Best Motion Picture, a character is having one of many “slice of life”-type conversations with a new friend who suddenly appears to be sick.

The friend explains that she has small-cell lung cancer, that it has metastasized to her brain, and that her doctors had given her seven or eight months to live.

Then she says, “I have this book called Final Exit by Dr. Kevorkian. Some people call him Dr. Death. It’s like various ways that you can end your life if you need to. It’s kind of like a recipe.”

The author, of course, is not Jack Kevorkian. But the mere movie mention sent book sales soaring.

It has not made me rich, but the consistent income from sales has been welcome, especially in my autumn years (born 1930).

Board of Directors

Executive Director

Quarterly Magazine

Vision

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

Mission

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

Final Exit Network
PO Box 10071
Tallahassee, FL 32302 • 866-654-9156
info@finalexitnetwork.org

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Hyperlinks are embedded in the digital copy of this magazine sent to every FEN member – online readers need only to click on a link.

Death didn't pause – *neither did Exit Guides*

By Lowrey Brown, FEN Director of Client Services

By the end of 2020, I was hearing people speak of "pre-pandemic" as though it were a geologic term, marking the time before tectonic forces shifted the ground beneath us. Now I am hearing people tentatively speak of "post-pandemic," always with the quick qualification that COVID isn't going away but feels manageable.

I am eager to leave behind those years of the pandemic itself – once seemingly endless, now being compressed in memory as a point on a timeline. But it is worth pausing to remember how scary it was.

We didn't really know what we were dealing with, the prospect of any kind of vaccine was distant, and hospitals were renting refrigerated trucks because crematoriums and funeral homes couldn't handle the number of dead. New York City was setting up temporary hospital beds in Central Park.

FEN put a hold on new applications but had an entire caseload of clients who were already in various places on their journeys. The first quarter of 2020 had seen a spike in applications, so we were working with a number of people who were ready, and who did not have a few months – let alone a few years – to wait out the virus. FEN's position was that guides should not travel until they felt comfortable doing so.

Apparently, guides interpreted that liberally. Looking back, there was a brief contraction, but even in April 2020, there was a guide visit. By May, there were a few, and it went from there.

From March 2020 through October of this year, 28 guides went on 101 visits, and almost half of those visits were in 2020 and the first half of 2021.

Thankfully, I am not aware of any COVID cases that resulted from those visits, but there could have been, and the consequences could have been serious or possibly fatal. I lack the words to adequately express the pride and gratitude I have for our volunteers, *so I will let their dedication speak for itself.*

‘Virtual’ advances!

– Online forum, VSED info, IT updates in works –

FROM EXECUTIVE DIRECTOR MARY EWERT

As we Midwesterners move from sunny summer into a blustery fall season, I’m thrilled to report on several volunteer-led efforts aimed at expanding FEN’s audience outreach in weatherproof cyberspace.

A website to list FEN’s trained end-of-life doulas, and their geographic coverage, is under development.

Jim Van Buskirk and **Deborah Alecson** are working on a virtual program featuring participant-led discussion with like-minded people about ideas, feelings, and concerns regarding choosing one’s own time of death. The program, ***Chosen Death Forum,*** is currently being piloted. If all goes well, it will be offered to FEN members on a rolling basis.

Watch this space for updates.

Ex-president **Janis Landis** and **Pam Bankert**, FEN’s attorney, developed a presentation titled ***Elder Care Attorney: First and Last Line of Defense***. The program, which qualifies for Continuing Legal Education (CLE) credit, discusses patient rights, as well as how and why they are too often ignored. It focuses on legal avenues to address these issues and provides information on how to advise clients seeking autonomy as they face end-of-life issues.

Janis also reports that the training class for **VSED doulas** was successfully completed for more than a dozen participants. *Professional Healthcare Representative Doula Training* is scheduled for early 2023. A website to list FEN’s trained end-of-life doulas, and their geographic coverage, is being developed.

Meanwhile, the **FEN virtual office** will soon see an upgrade to our database. I ask for your patience as we transfer membership records from our antiquated system to a newer model. We hope the transition will be seamless, but bumps in the road seem inevitable when dealing with technology.

FEN continues to be generously remembered in **bequests**, which are deposited in our Fidelity investment account and monitored by our Audit & Finance Committee.

The 2022 **Annual Appeal** should arrive in your mailbox soon. Your continued support sustains our Exit Guide Program as well as our outreach initiatives.

Since at least the summer 2021 issue of this magazine, we have received many tips from you, our members, that provided **touching EOL human-interest stories** – about people who chose their time of death in the face of disapproval from some; relatives who failed to do any end-of-life planning; people with disabilities who don’t want to be excluded from access to aid in dying; and adult children who witnessed horrifying deaths of parents they loved because those parents could not get the peaceful death they wanted and deserved.

I’m issuing a renewed request to you all: Do you have a story to share with us?

In this issue, FEN **Surrogate Consultant Althea Halchuck** shares the story of Sue K., who encountered so many stumbling blocks as she tried to help her spouse achieve the peaceful death he wished.

Reader response to these stories is overwhelmingly positive. With that in mind, I’m issuing a renewed request to you all: Do you have a story to share with us? Do you want to write it, or are you willing to be interviewed by our editor, who will then write it for your review?

Send an email to **info@finalexitnetwork.org**. We’ll get in touch. This is your magazine. *Help us keep it relevant to you, our valued audience.*

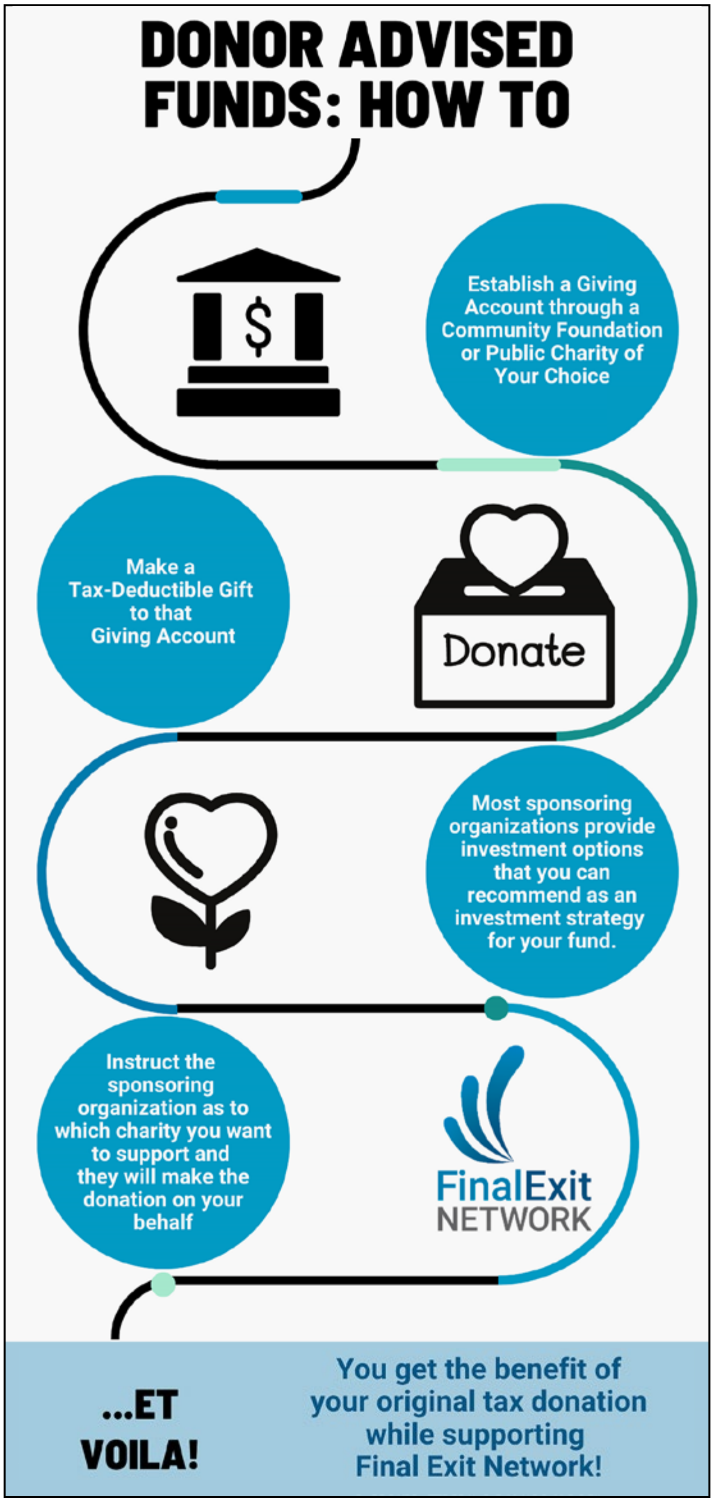
DAF offers simple way to support FEN

There are many ways to support FEN, and we are grateful for each one! From time to time, we will highlight a method of giving that may be of interest to you. This issue, we are featuring Donor Advised Funds.

What is a Donor Advised Fund (DAF)? In short, it's a private fund at a public charity or community foundation that manages charitable donations on your behalf, while providing tax advantages to you as the donor. Many require no minimum balance and accept both cash and non-cash assets. Once a DAF is established, you can instruct the sponsoring charity to which organization to direct your donation.

In 2021, nearly $160 billion was held in Donor Advised Funds, providing charitable assets to thousands of nonprofits globally.

For information on how to support Final Exit Network through a Donor Advised Fund, contact us at 866-654-9156 or info@finalexitnetwork.org



DONOR ADVISED FUNDS: HOW TO

Establish a Giving Account through a Community Foundation or Public Charity of Your Choice

Make a Tax-Deductible Gift to that Giving Account

Most sponsoring organizations provide investment options that you can recommend as an investment strategy for your fund.

Instruct the sponsoring organization as to which charity you want to support and they will make the donation on your behalf

...ET VOILA!

You get the benefit of your original tax donation while supporting Final Exit Network!

Court clears Belgium over contested euthanasia case

The European Court of Human Rights ruled in October that the Belgian state didn't violate the rights of a person suffering from depression when it accepted her decision to go ahead with a euthanasia procedure.

Judges found in favor of Belgium in three out of four counts, only finding fault over how the government conducted a review after the death.

The case revolved around Godelieva de Troyer, who was 64 when the procedure was carried out in 2012. She had been suffering from chronic depression for some 40 years when she approached oncologist Wim Distelmans to ask him to help her die.

Distelmans is a high-profile activist who campaigns for assisted-dying in Belgium.

"At the end of the interview, the doctor concluded that she was severely traumatized, that she had a serious personality and mood disorder, and that she no longer believed in recovery or treatment. He agreed to become her doctor under the Euthanasia Act," reads a summary of the court's findings.

The complaint was taken to the court by Tom Mortier, de Troyer's son, who said he wasn't properly informed of the decision to euthanize his mother. The court noted that he received an email from his mother in which she stated her wishes, and he did not reply. However, de Troyer did not want to call her children, for fear of delaying her death.

Mortier was informed the day after she died.

The court found that neither Belgium's legislative framework for euthanasia, nor its application in this case, violated the European Convention on Human Rights, which guarantees the right to life.

Is a ‘completed life’ enough?

Gray areas part of FEN eligibility criteria

By Lowrey Brown, FEN Director of Client Services

In our summer magazine, we shared Adrienne Germain’s final letter and noted that she had not used FEN’s Exit Guide Program, as it does not accept “completed life” applications. That probably wasn’t the best wording to use, and it caused some confusion, as the concept of a completed life is at least partially captured by our guide program criteria.

Years ago, right-to-die advocates spoke of “old-age rational suicide” – when mentally competent, thoughtful individuals reach an age when their quality of life has significantly diminished choose to die rather than slog to the bitter end. Replacing that terminology, the idea of a completed life seems to be in vogue these days.

A completed life for me is different than a completed life for you. It is not a concept that can be neatly defined. That said, if we surveyed a thousand people, we might get a thousand different answers, though common themes and values would, no doubt, emerge. I will hazard a guess that one of those themes would be what Germain expressed when she wrote, “The loss of physical health and stamina curtails my independence and my ability to enjoy life as fully as I wish.”

An individual’s inability to engage in life in a satisfying way would likely be a significant factor in her decision that her life was complete. Other psychosocial issues can also contribute to a sense of completion, such as the loss of one’s partner or close friends, sensing one’s personal agency fading, or a diminishing ability to live as independently as one wishes.

One Exit Guide Program’s acceptance criteria is a constellation of intractable medical conditions that, taken together, significantly impair quality of life. Aches, pains, reading glasses, and hearing aids may be a normal part of aging. However, a combination of severe arthritis or neuropathy that makes it painful to move, bladder or bowel difficulties, digestion problems, diminished eyesight such that reading is challenging, and hearing loss that causes social isolation and loss of agency can render someone as homebound as a late-stage neurodegenerative disease. These are the kinds of situations that the “constellation of conditions” criterion addresses.

Would Germain have qualified for guide support? We don’t know – she did not apply – but the description in her letter suggests that she was not debilitated enough. We are sometimes asked, given that it is impossible to know how someone views their quality of life, why we do not support all rational adults who wish to exercise autonomy at the end of life.

We at Final Exit Network have neither the wisdom nor the moral authority to judge for another whether their life is complete, and we respect the right of all competent adults to choose their own endpoints. Our volunteers direct thousands of callers to publicly available literature so they can, as Germain did, choose for themselves when they deem their life complete.

The Exit Guide Program does not serve everyone. We serve those suffering irremediably from medical conditions that have or soon will destroy their quality of life. To serve those who say their life is complete – without other, medical criteria – would be to serve everybody, because who can say that another's life is not fulfilled? Our approach is the most liberal of any right-to-die group in the country, making us a target for those opposed to choice in dying.

If we wish to move social norms toward a more compassionate approach to choice in dying, it does not behoove us to antagonize the society in which we serve. That could expose the organization and our guides to an unacceptable level of risk.

At a philosophical level, we serve those whose choice to end their life is well-considered and undertaken with a deep respect for self and others. The requirements of medical records supporting the applicant, and that the client's closest loved ones be in concert with their choice, represent these values.

We make no claims of perfection in our criteria or of having found the "right" answer, if one exists, or that we will not change our criteria. But we recognize that many chosen deaths are poorly considered and deeply tragic, as competent as the individuals making those choices may be.

The Exit Guide Program's criteria are an important safeguard to ensure that those we serve end their lives in concert with our commitment to our values and the need to protect the integrity of the organization.

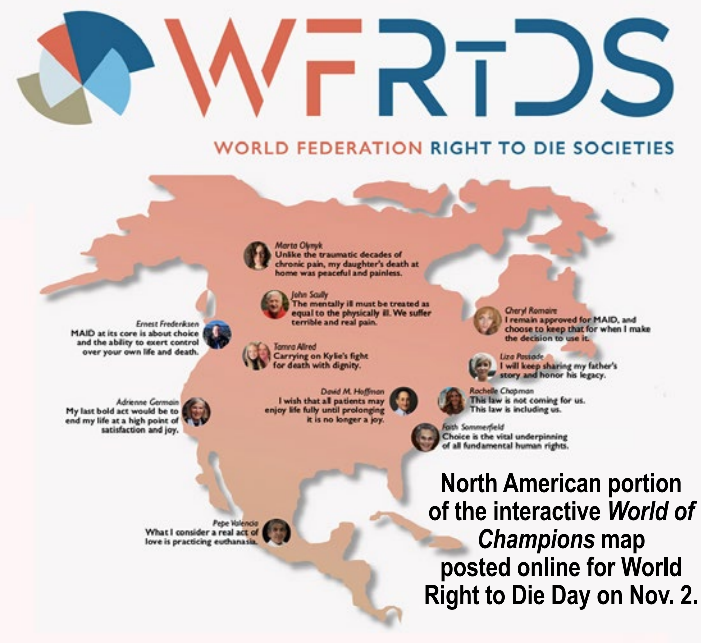
Federation conference lauds DWD 'champions'

FEN recognizes Chapman, Germain

FEN Board President Brian Ruder and Executive Director Mary Ewert were among those who represented Final Exit Network Nov. 2-6 at the biennial conference of the World Federation of Right to Die Societies.

FEN joined 57 other RTD groups from 30 nations to kick off the Toronto meeting by simultaneously posting a *World of Champions* map for World Right to Die Day, Nov. 2. The map tells individual stories of people around the globe who work to make "death with dignity" possible.

FEN was invited to nominate two of the 11 North Americans singled out for praise: Rachelle Chapman and the late Adrienne Germain. (Both have been featured in this magazine, and their views can be found via the map on the FEN website: finalexitnetwork.org)



North American portion of the interactive *World of Champions* map posted online for World Right to Die Day on Nov. 2.

Chapman is a powerful voice who advocates for the rights of persons with disabilities – but she does so on behalf of RTD options, blasting the fallacious argument that MAiD puts them at risk.

Germain, 75, was a world advocate for women's rights who had a planned, dignified death in May.

Canadian Senator Pamela Wallin delivered the keynote address for Saturday's session of the conference. She spoke of her ongoing effort to include a dementia Advance Directive in Canadian law, which would allow patients to consent in advance, prior to the loss of mental capacity, to Medical Aid in Dying.

FEN's Mary Ewert (r) with Bev Heim-Myers (l), chair of Dying with Dignity Canada, which hosted the meeting, and keynote speaker Sen. Pamela Wallin.

Wallin spoke about her own experience caring for her mother, who suffered from Alzheimer's and rebutted the "happy dementia patient" narrative that some MAiD opponents put forth.

She also warned about the dangers of misinformation, which is growing as the opposition pushes back against the possibility that an AD might be recognized in Canadian law.

From: Sue K <[redacted]>
Subject: Request for help
Date: June 4, 2021 at 11:17:46 PM EDT
To: Althea Halchuck <fensurrogate@gmail.com>

I am Medical POA for my husband, Bill, who is in memory care, suffering from vascular dementia. We have been married for over 30 years and we promised each other that we would never allow prolonged suffering if one of us were diagnosed with a terminal condition. I have been trying to talk to Bill's doctor about his wishes not to be treated for his co-morbidities and to receive comfort measures only.

My calls and emails have gone unanswered. Neither of us wants life-prolonging measures; we want quality of life or no life at all. I would love your guidance & support in helping me get the doctor and care home to start honoring Bill's advance directive and to stop prescribing meds and tests since they are not benefitting him.

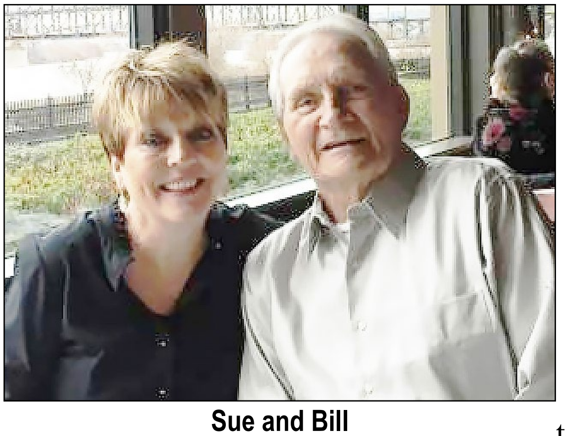
FEN's surrogate consultant answered a wife's plea to help her dying husband

By Althea Halchuck, FEN Surrogate Consultant

Above is the email I received from Sue K., and I provided support until Bill's death in January 2022.

FEN created the national Surrogate Consultant Program offering "in the heat of the moment" guidance to surrogates and patients when medical staff disregard an Advance Directive or POLST (Physician Orders for Life-Sustaining Treatment). This innovative program aims to empower the patient or surrogate to help themselves honor the patients' legal rights.

The issue might be a doctor demanding the patient receives unwanted medications or tests, or a hospice refusing to give adequate pain meds. My role is to help surrogates enforce the patient's Advance Directives. I do not recommend specific medical treatment or offer legal advice, but lay out a client's range of options and potential impact of any decisions.


Sue and Bill

FEN's attorney is available for free to guide the next steps if an impasse arises for a member.

Sue was a proactive surrogate but needed some tools to help in her quest to get Bill the care he wanted. In February, Bill's doctor declared him incapacitated, and Sue and the facility doctor signed a POLST, which helps patients receive the medical treatment they have requested and avoid procedures they do not want. (Google for your state's POLST.)

Bill's Pennsylvania POLST indicated "Comfort Measures Only," DNR, and no antibiotics. A dementia medication, Seroquel, was to continue because it helped his symptoms.

Sue worked full-time, and Bill's memory care was in COVID lockdown for many months, so reading his chart or talking face-to-face with staff was impossible.

Sue was frustrated and exhausted dealing with providers who made false promises or refused to respond to her calls. The doctor and facility stonewalled her at every turn. They kept telling her they would eliminate the medications and stop unnecessary tests.

It was only lip service, because the doctor who had signed the POLST ordered an echocardiogram in June, a burdensome test and not a comfort measure. Sue said: “The scripts to be discontinued were refilled on Dec. 16.”

FEN’s attorney reviewed all the documents, offered advice from the sidelines, and volunteered to step in – but Sue wanted to try to handle this on her own. I suggested she ask for a hospice evaluation or palliative care consult, to remove his care from the facility doctor.

Unfortunately, Bill did not yet qualify for hospice, but they agreed to evaluate him quarterly. In August, Sue (at my urging) sent the doctor and facility a certified letter outlining his treatment and demanding his medical records. In September, she began working with an elder attorney to create a trust, and he sent the doctor a similar letter.

Finally, in November, the doctor claimed they would reduce Bill’s meds on Dec. 9, and Sue was able to obtain Bill’s medical record from the facility nurse. I suggested Sue review Bill’s chart at every visit to check his meds, or see if they treated him with any antibiotics – a direct violation of his POLST.

The doctor never explained why he was waiting three months to wean Bill from the unnecessary drugs or why he refilled them on Dec. 16.

Sue was a willing and dedicated surrogate and followed most of my advice during the many months we worked together for Bill’s benefit. Had it been requested, FEN was prepared to file a *pro bono* lawsuit against the doctor and facility for disregarding his POLST and Advance Directive.

Sue’s Testimonial

“In January 2021, I heartbreakingly had to admit my husband into memory care due to his dementia progression. I was taken aback by the lack of communication between me, as Bill’s Healthcare POA, the care facility, & the facility’s physician. My numerous phone calls & voicemails to discuss his care went unanswered. I was at wit’s end and knew I needed the help of a professional healthcare advocate and found Althea.

“She was the best surrogate educator, and coached me throughout the year-long ordeal until Bill’s passing on Jan 2, 2022. Althea and Final Exit’s Surrogate Consultant Program was a Godsend during my husband’s year in a memory care facility.”

In December, Bill developed end-stage heart failure and went into hospice. He died on Jan. 2. Sue said she “fought for Bill to the end and even demanded more morphine.”

Through it all, the Surrogate Program worked as designed and helped give Bill and Sue the peaceful ending he envisioned in his EOL planning.

Contact Surrogate Consultant Halchuck online or by phone (800-491-6713) with issues surrounding surrogacy, or view this short introductory video.

New challenge to MAiD residence requirements

Another shot has been fired at states’ residence requirements for access to Medical Aid in Dying (MAiD).

A terminally ill Connecticut woman is suing Vermont to drop its residence mandate on the heels of Oregon’s late-March decision to do so.

Bridgeport, CT, resident Lynda Bluestein, along with a Vermont physician, filed suit in late August in U.S. District Court in Burlington arguing that the requirement for MAiD patients to reside in-state violates the U.S. Constitution.

Bluestein, 75, was diagnosed with breast cancer in 2018, followed by malignant melanoma a few months later. In 2021, she was told she had end-stage fallopian tube cancer, and she told Vermont Public Radio on Sept. 22, “In that moment, I realized that I am indeed following my mother, who also had three individual cancer diagnoses and died a death that she would not have wanted for herself, and I certainly don’t want that.”

Connecticut, where she lives, does not allow MAiD, though it has been proposed several times. The lawsuit asserts that Vermont’s MAiD law violates three clauses in the U.S. Constitution: Privileges and Immunities, Dormant Commerce, and Equal Protection.

A similar suit in Oregon was settled out of court this past spring when the state required officials to issue directives halting enforcement of the residence provision, and initiate a legislative request to permanently remove residency language from the law.

The common-sense reasoning behind the challenges is simple: Nothing prevents Americans from traveling to other states for medical procedures, so why should they be stopped from going elsewhere for a process to end their life when dying?

The issue has come further to light with states offering abortion services (where legal) to non-residents after Roe v. Wade was overturned.

Ruth Gordon and Bud Cort had a short but wild ride in the controversial film *Harold and Maude*.

Was Maude ahead of her time?

She may have lived a first 'completed life'

By Jim Van Buskirk,
FEN Member / Chief Reviewer

In honor of the recent 50th anniversary of *Harold and Maude*, I revisited this counter-cultural classic film.

Written by Colin Higgins, directed by Hal Ashby, and filmed throughout the San Francisco Bay area, this 1971 controversial black comedy became a touchstone for many (including me), while viewed as "tasteless" by others.

When death-obsessed 19-year-old rich kid Harold first meets the aging Maude at a funeral, she says: "I'll be 80 next week. A good time to move on, don't you think? ... I mean, 75 is too early, but at 85, well, you're just marking time and you may as well look over the horizon."

> ***Maude has been articulating what is referred to as an early, unacknowledged example of* ‘a completed life’ *– or rational, old-age suicide.***

Soon thereafter, at another stranger's funeral, she says "... They're such fun, aren't they? It's all change. All revolving. Burials and births. The end to the beginning and the beginning to the end – the great circle of life ..."

A little later, as Harold interrogates Maude's penchant for appropriating other peoples' cars: "What owners, Harold? We don't own anything. It's a transitory world. We come on the Earth with nothing, and we go out with nothing, so isn't 'ownership' a little absurd?"

Regarding her friend Glaucus's ice sculpture, Harold notices that the ice is melting. "Yes," Maude agrees, "that's one of the drawbacks of the medium."

Another expression of life's fleeting nature: ‘“And this, too, shall pass away.' Well, the wise man was right – if you remember that, you can't help but live life fully."

Sitting in a field of flowers, Maude muses, "They grow and bloom, and fade, and die, and some change into something else. Ah, life! ... I should like to change into a sunflower most of all."

Maude's nattering slowly starts to sink in as her profound perspective pervades the film – and Harold's psyche. After Harold confesses to his first suicidal prank, ending with, "I decided then I enjoyed being dead," Maude responds, "Yes. I understand. A lot of people enjoy being dead. But they are not dead really. They're just backing away from life. They're players – but they sit on the bench. The game goes on before them. At any moment they can join in. Reach out! Take a chance! Get hurt maybe. But play as well as you can. Go team, go! Give me an

'L.' Give me an 'I.' Give me a 'V.' Give me an 'E.' LIVE! Otherwise, you'll have nothing to talk about in the locker room."

When Harold surprises her for her 80th birthday and proposes marriage, Maude tells him: "Oh, I am happy, Harold. Ecstatically happy. I couldn't imagine a lovelier farewell."

Harold: *Farewell?*

Maude: *Why yes. It's my 80th birthday.*

Harold: *But you're not going anywhere, are you?*

Maude: *Oh yes, dear. I took the pills an hour ago. I should be gone by midnight.*

In the ambulance and then the hospital, Maude chides Harold.

Maude: *Oh, Harold! What a fuss this is. So unnecessary.*

Harold: *Maude, please. Don't die. I couldn't bear it. Please, don't die.*

Maude: *But, Harold, we begin to die as soon as we are born. What is so strange about death? It's no surprise. It's part of life. It's change.*

Harold: *But why now?*

Maude: *I thought 80 was a good round number ...*

Harold (to medical staff)**:** *Please, don't you realize? She is dying.*

Maude: *Well, not dying, actually. I'm changing. You know, like from winter to spring. Of course, it is a big step to take.*

Throughout the film, we now realize, Maude has been articulating what is referred to as an early, unacknowledged example of *a completed life* – or rational, old-age suicide. Harold wasn't really listening, and the audience wasn't taking her seriously.

Harold tries to save his elderly lover, but to no avail. However, Maude has left him with the greatest gift: a newfound love for life.

Now that I'm closer in age to Maude than Harold, I embrace her philosophical approach: "Farewell, Harold. It's been all such fun."

Tourist attraction offers last chance for souvenirs

Outlandish famous WI landmark

An interesting juxtaposition of signs (above) was captured in August by a FEN member visiting Wisconsin's "unusual" *House on the Rock.* He wasn't sure what trinkets and memorabilia might be offered to tourists heading toward the "Final Exit."

The *House*, opened in 1959, is a sprawling complex of architecturally distinct, themed rooms, streets, gardens, and shops designed and added to over many decades. It boasts the world's largest indoor carousel and has varied collections that some might mistake for museum exhibits.

More Good Endings

Book & Movie Reviews by Jim Van Buskirk

Last Flight Home

Ondi Timoner, director – 2022

"On an unremarkable suburban street, we find Eli Timoner in his final days and discover an extraordinary life, one filled with wild achievements, tragic loss and, above all, enduring love from his incredibly close-knit family. *Last Flight Home* shares an unforgettable and stunning verité account of a family courageously facing both life and death."

This logline of Ondi Timoner's film about her father's final journey doesn't quite capture the depth and intimacy of this uplifting and heart-wrenching documentary.

At 92, Eli, suffering from COPD and congestive heart failure, is in pain, bedridden and totally dependent on those around him. Of sound mind, he clearly and repeatedly states his desire to die.

His family lovingly guides him through California's Death With Dignity (Medical Aid in Dying) protocol. While impatiently waiting the requisite 15 days between physician requests, Eli says goodbye to friends, family and caregivers. (As of January 1, 2022, the waiting period between the first and second oral request is reduced to 48 hours).

His daughter Ondi (Director/Producer/Writer/Editor/Director of Photography) justifiably includes herself in many of the intimate scenes, while her sister, Rachel, balances her role as daughter as well as Eli's rabbi. Eli's devoted wife, Lisa, and their son, David, also play important roles, taking advantage of the unwanted wait, as the assembled share words of wisdom, of gratitude, even an off-color joke.

Interspersed into the day-by-day countdown is the family's remarkable story, expertly using home movies, commercials, and other vintage footage.

As Ondi describes her father: "Eli was innately good. He always instinctively said and did the right thing. He was also a maverick, who founded the fastest-growing airline in the world before suffering a stroke, due to his neck being cracked by a masseuse, which paralyzed his whole left side at 53 years old.

"The way Dad handled his suffering over the next 40 years – with stoicism, grace and humor – made him a model to us all. He was always positive, despite carrying great sadness and regret for having lost his physical autonomy, independence, status and financial means after being pushed out of the airline he founded due to a lack of protections for the disabled in the early '80s."

That this uplifting film focuses on a Jewish patriarch and his family makes it no less universal. Interestingly, an italicized editor's note precedes Simi Horwitz's sensitive review in the forward: "This article contains discussion of suicide." As if an incapacitated nonagenarian's decision to hasten his own death could be considered *suicide.*

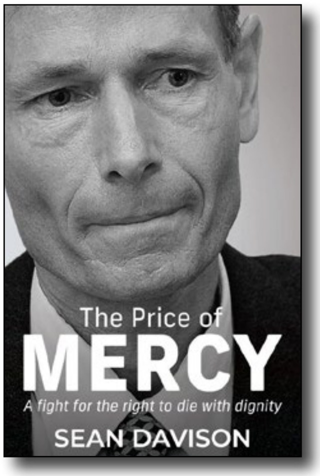
[Having won the best documentary prize at the 23rd annual Woodstock Film Festival, the movie was acquired by MTV Documentary Films for a fall theatrical release.]

The Price of Mercy

By Sean Davison (2022)

"The last 48 hours have been the most harrowing of my life. I've been incarcerated in a prison cell in Cape Town, South Africa, charged with the premeditated murder of Dr. Anrich Burger who died five years ago, in 2013."

Sean Davison's memoir, The Price of Mercy, written during his time as a prisoner, is structured in the form of journal entries, beginning with "The Arrest: Wednesday 19 September 2018."



The former President of the World Federation of Right to Die Societies and founder and director of Dignity South Africa focuses here on his roles as professor, husband, and father of three, as he dispassionately narrates his grueling legal and stressful emotional journey.

"I sit on the cold floor. My mind can't stop spinning. Sleep seems like an impossibility. I can't believe that just 10 hours earlier I had been making my final preparations to fly back to Australia to rejoin my family."

In June 2019, he was convicted in Western Cape High Court on three counts of premeditated murder after three men – Anrich Burger, Justin Varian, and Richard Holland – who had been suffering from unbearable pain, asked Davison to help them end their lives.

In a plea bargain agreement with the state, Davison was sentenced to house arrest for three years, ending on June 20, 2022, and was banned from speaking to the media for the duration of his sentence. The case received international attention, including support for Davison from Archbishop Desmond Tutu.

Davison has written several books on his personal experiences in the right-to-die movement. His first, Before We Say Goodbye, describes the three months in 2006 he spent with his terminally ill, 85-year old mother prior to helping to hasten her death. Edited by the publisher to remove anything that might lead to his arrest, Davison was later convinced by American author and publisher Elaine Feuer of the importance of telling his uncensored story and bringing it up to date with events that occurred after its publication.

In 2015, his second book, The Last Waltz: Love, Death & Betrayal, which includes his court trial, was widely acclaimed and became part of a trilogy including Feuer's To Gently Leave This Life: The Right to Die and Traveling In and Out of Heaven, all of which have been used to assist United States right-to-die organizations.

The Price of Mercy compellingly chronicles one man's agonizing journey as he remains selflessly unwavering in his belief that we all have the right to die on our own terms.

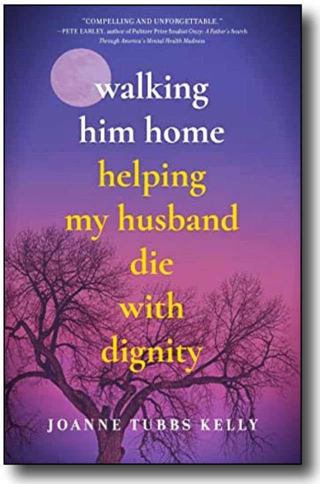
Walking Him Home ...

By Joanne Tubbs Kelly (2022)

The Last Ten Days ...

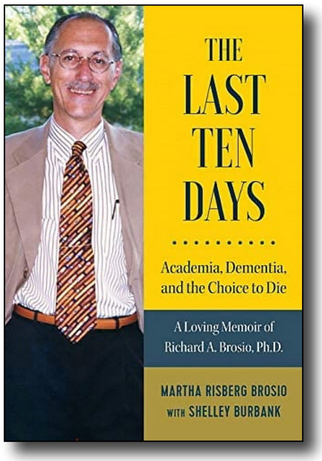
By Martha Risberg Brosio (2019)

These two memoirs, by women who escorted their husbands through their final days, offer an intimate glimpse into the real meaning of "in sickness and in health, until death do us part," adding to the growing canon of widows supporting their husbands' hastened deaths and honoring their memories.



After his 2013 diagnosis of Primary Progressive Aphasia, a type of dementia similar to Alzheimer's affecting the brain's front and temporal lobes, Richard Brosio decided to voluntarily stop eating and drinking, leaving his devoted wife to document the trajectory of the disease and their lives together.

The chapters titled "Day One" through "Day Ten" detail both Richard's final days as well as the couple's 32-year relationship in Milwaukee. Martha Risberg Brosio straightforwardly states her intention in the prologue: "My hope is that this memoir, while chronicling the last 10 days of Richard's life as well as the story of our relationship and of Richard's work as an education researcher, writer, and teacher, will inspire those who are interested in further construction of education for democratic empowerment, social justice, respect for diversity, and the possibilities for a more caring school and society.



"I also hope it will be helpful to people when they and their loved ones face a devastating diagnosis of dementia with the knowledge that there is no cure."

She generously allows their two teenage granddaughters the final reminiscences in this poignant and powerful memoir.

Alan Kelly's diagnosis was somewhat similar: Multiple System Atrophy (MSA), a rare nervous system condition causing gradual damage to nerve cells in the brain. Living in Colorado, however, allowed Alan more end-of-life options, including Medical Aid in Dying.

Joanne shares her many conflicting emotions about Alan's disease, his decision, and her frank appraisals of physicians, hospice workers, and other caregivers, including severe criticism of some and heartfelt appreciation for others. And she acknowledges her own essential role in the process: "... despite the fact that I loved him dearly and did not want him to die, ... he couldn't have pulled it off if I had refused to help him."

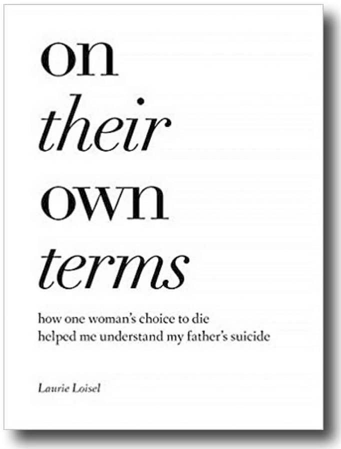
Opening with the scene of Alan Kelly's final breath in January 2020, the book then flashes back to 1993, chronicling the couple's complicated relationship history, through Alan's death and Joanne's grieving process. Her vivid attention to details invites the reader to experience her fortitude, fears, and frustrations. A few pages of selected resources contribute to this book's usefulness.

These titles join In Love, Amy Bloom's recent "memoir of love and loss" about accompanying her husband, diagnosed with early-onset Alzheimer's, to *Dignitas* in Switzerland.

Three devoted wives with husbands dealing with cognitive decline who have made three different, difficult choices, reluctantly support their beloved spouses. (Might there soon be a memoir about using Final Exit Network's support services?)

On Their Own Terms ...

By Laurie Loisel (2019)



This short book (164 pages) by Laurie Loisel packs an important punch, as it describes, compares and contrasts the shotgun death of her father, Paul Loisel, with that of Lee Hawkins, who voluntarily stopped eating and drinking.

A freelance journalist in Northampton, MA, Loisel chronicles her father's life and death, and the family's decision to be explicit about his suicide. Her article, "My family's decision to tell the truth about my father's suicide," elicits an unexpected revelation: The death of Paul's brother Don had not been natural as previously claimed, but also a shotgun suicide. The author sensitively explores the effects of secrecy and shame on the extended family's grieving process.

Another result of the controversial article was a letter from Lee, whom Loisel had not previously met and whose life and VSED death she goes on to robustly recount. That some chapters are reprinted articles from the *Daily Hampshire Gazette* only adds to the book's immediacy, as do the well-chosen black-and-white photographs. An addenda offers additional articles, letters, and obituaries, followed by "discussion prompts," making this a valuable resource for friends and family to discuss end-of-life options.

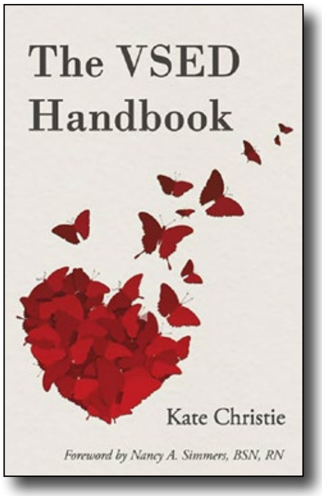
Loisel pulls no punches in her position: "But the fact is, Maine's now-adopted Death with Dignity law would not have helped my father. Nor, had there been one in Massachusetts, would it have been any help to Lee. People like Lee and my father – elderly people facing the slow and natural decline of old age with no terminal diagnosis – generally find no recourse in assisted-suicide laws.

"They fall into a category that no legislation has addressed and many families find excruciating to discuss. So the question remains: Do people have the right to hasten their deaths when living has become something they no longer want?"

The VSED Handbook

By Kate Christie (2022)

This 72-page booklet straightforwardly and simply demystifies the process of VSED. Using her personal experience of having supported her mother through the journey, the author offers basic tips such as working with hospice, palliative care, and/or a death doula. Her repeated emphasis is on planning, for the person, family members, and caregivers.



Lists of useful supplies, various documents and directives, a timeline of what to expect, a sample personal statement, resources, and other helpful ways to prepare, make this a very user-friendly addition to the available materials around VSED.

Those seeking a more rigorous approach might want the 312-page tome Voluntarily Stopping Eating and Drinking: A Compassionate, Widely-Available Option for Hastening Death. Published last year, and edited by experts including Timothy Quill and Thaddeus Pope, it "provides a realistic, appropriately critical, yet supportive assessment" of VSED. The integrated, multi-professional, multi-disciplinary approach makes it useful for a variety of readers: patients and/or their families considering end-of-life options, clinicians, ethicists, lawyers, and institutional administrators.

THE BACK PAGE

A COMPENDIUM OF RIGHT-TO-DIE WORLD NEWS

United States

A recent study shows that 74 percent of U.S. MAiD users between 1998 and 2020 had cancer, though patients with any terminal illness may qualify.

However, data suggest that oncologists may not feel familiar with MAiD or be prepared to support patients who ask about it.

In a 2021 survey, 18 percent of gynecologic oncologists said they did not know if their state had legalized MAiD. Of the respondents who lived in states where MAID is legal but chose not to provide it, 36 percent said they did not provide it because they had limited knowledge about it.

Physicians who are opposed to assisted dying due to ethical concerns, religious reasons, or professional views – such as a preference for palliative care – have the right to refuse providing MAID.

France

- Jean-Luc Godard, 91, the French-Swiss director who revolutionized European post-war cinema, died by MAiD in Switzerland in September.

The medical report said he chose to end his life. He “had recourse to legal assistance in Switzerland for a voluntary departure” because he was “stricken with ‘multiple incapacitating illnesses,’” said Godard’s legal counsel.

The influential director was said by his family to have died “peacefully at home” with his wife, the Swiss filmmaker, Annie-Marie Miéville.

- In a step toward codifying end-of-life laws, the French government is convening a citizens’ convention of 150 randomly chosen people to debate the subject and suggest possible legislative changes.

The convention will meet from December to March in an effort to answer a specific question: “Is the framework accompanying the end of life adapted to different situations, or should changes be introduced?”

Based on the answer, France will decide – or not – to change the so-called “Claeys-Leonetti” law that bans euthanasia and assisted suicide.

President Emmanuel Macron has promised reforms (while ignoring the Pope’s protest), including possibly allowing an “active aid to die,” which the country’s national ethics consultation committee said in September could be possible with strict conditions.

The committee, and Macron, have said that this is not an issue to be put to a referendum.

The Netherlands

Campaigners calling for the decriminalization of assisted suicide took the Dutch government to court in October, arguing that its ban on helping a person end their life breaches human-rights norms.

This, despite the fact that their country has the most liberal RTD provisions in the world. Still, it’s against the law for private citizens to help anyone die.

The case at The Hague District Court is the latest legal battle in a long-running debate around end-of-life issues in the country that in 2002 became the first in the world to pass a law that decriminalized euthanasia.

The court was asked to declare that the Dutch state is “acting unlawfully by denying its citizens the right to die with dignity under their own control.”

Cooperative Last Will, which says it has nearly 30,000 members, wants the case to force a change to decriminalize assistance for people who want to take their own life at a time of their choosing and for a lethal substance to be made available under strict conditions.

The Dutch government argues that many people who want to end their lives can make use of the existing euthanasia law. “However, the state is not obliged – and that is what this is all about – to facilitate assisted suicide, let alone allow it under all circumstances,” a government lawyer said.

Colombia

The country’s Health Ministry reports that between 2015 and Aug. 31, 2022, 316 euthanasia procedures took place – more than half in the past two years (95 in 2021; 95 in the first eight months of 2022).

The majority of patients were facing imminent death, and up until 2021, euthanasia had only been allowed in terminal cases.

After a new ruling by the Constitutional Court, however, “Nowdays, a person could say that the problem of dignified dying and end-of-life decisions is over,” said Lucas Correa, research director for the Economic, Social and Cultural Rights Laboratory.

Now anyone with “intense physical and psychic suffering, due to bodily injury or serious and incurable illness” may choose to die a dignified death, he said.

Recent high-profile cases included a woman who, after suffering serious health problems, decided she wanted to end her life so as not to burden or have to depend upon anyone else to care for her.

FINAL EXIT NETWORK
PO BOX 10071
TALLAHASSEE, FL 32302

New board member

‘Mentor’ schooled him in MAiD

By Jay Niver, FEN Editor

Dr. Jay Schamberg

Jay Schamberg, MD, was named to the FEN Board of Directors at its meeting in July. But his right-to-die mindset was determined about 40 years earlier as a young medical intern.

“I had a mentor who believed in helping people at the end,” he recalls. Dying patients with no hope – who asked for relief and whose family all agreed – were “helped” by the physician, he explained. “He was beloved. No one ever reported him.”

That Kevorkian-like passion helped Schamberg’s own mother in 1978. He recounts, “My mom was sick with throat cancer, and she had told me clearly, ‘I want to die at the time and place I choose.’ So I called (his mentor), and he came and gave her a lethal dose of morphine.”

That wasn’t the end of it, says Schamberg. After leaving Mom, some time later, “the light went on in her room. She sits up and says, ‘Aren’t I supposed to be dead?’”

The morphine just needed more time to work, and it did in the end.

Schamberg’s path to becoming a physician was not a crow’s flight. He explains, “My grandfather was a doctor, and my dad was a doctor, and it was always assumed I would follow in their footsteps. So, growing up I was determined *not* to be a doctor.”

Instead, he got an undergrad degree in political science, and nine years elapsed until he could place “MD” after his name. Then he worked eight years as a Milwaukee pathologist before managing laboratory operations for two major hospitals over 17 years. Before retirement in 2011, he was responsible for all lab operations for Advocate and Aurora healthcare systems in Milwaukee and Chicago, with a $300 million budget.

Schamberg’s FEN introduction came via Ann Mandelstamm, who found room for him in a 2017 class for Exit Guides. On the way to become one, he joined the Medical Evaluation Committee in 2018, chaired the MEC last year and recently returned to head it again. That, plus board duty, will keep him busy with Final Exit Network.

Besides end-of-life issues, Schamberg enjoys reading and wine – not necessarily at the same time. His wife, Anne, wrote a wine column for 30 years, though neither claims to be a connoisseur.

They used to travel a lot, but he admits he is “slowing down” and “happy as a clam” in Wisconsin retirement. Meanwhile (just a coincidence), Anne for now is in Brooklyn, NY, “helping take care of grandkids,” of which their three children have six to keep the families humming.