Final Exit
NETWORK

The Human Right To A Death With Dignity

In This Issue

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> If she'd been open to having trained Guides ... I am 100 percent convinced she would have died quickly the first time.

4 DIY tries proved: *A Guide makes all the difference*

Mom, a diabetic, ordered a milkshake with her *second* "last meal." She joked, "Maybe this will kill me!" It did not.

By a FEN Exit Guide

I've always felt strongly that people should have the option to end their lives when their quality of life is no longer acceptable.

My mother's parents wanted to avoid prolonged deaths and wished to be compassionately put to sleep, like their beloved pets. My grandmother died quickly of a stroke, but my mother and I watched my cancer-ridden grandfather linger in the hospital. We pleaded with staff to somehow hurry the process. All they could do was help with pain. It took him three weeks to die, and that was just too long for him and for us.

This experience informed my mother's end-of-life choices, and Mom did not want a long death in a hospital or nursing home. She was in her late 50s and very healthy, so figuring out her own plan was not pressing.

When she reached her 70s, my mother had a simple little accident that pushed her to the brink of wanting to end her own life: One night she got up to use the bathroom, and she slipped and fell. She was in pain and called an ambulance to take her to the emergency room.

An X-ray showed a fractured vertebra, so Mom was admitted, and a surgeon repaired the crack. For a few days she felt better, but then, the pain became unbearable, even worse than how she felt when she was first injured.

For the next two months, she was in constant pain. She visited many doctors and had three visits to the ER, two of which ended in hospital stays. X-rays, MRIs, and different pain medications and upped dosages made no difference.

After these unsuccessful doctor appointments, emergency room visits and hospitalizations, my mother gave up on the medical community's ability to help her find relief. She could not live with this excruciating pain, and she wanted to end her life.

Since I had witnessed what she was going through, I was on board with her decision. We discussed self-

GUIDE – *continued on page 2*

GUIDE

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deliverance options: buying a gun, jumping off a bridge, swallowing all the pills and alcohol in the house, or breathing carbon monoxide in a running car with a hose on the tailpipe.

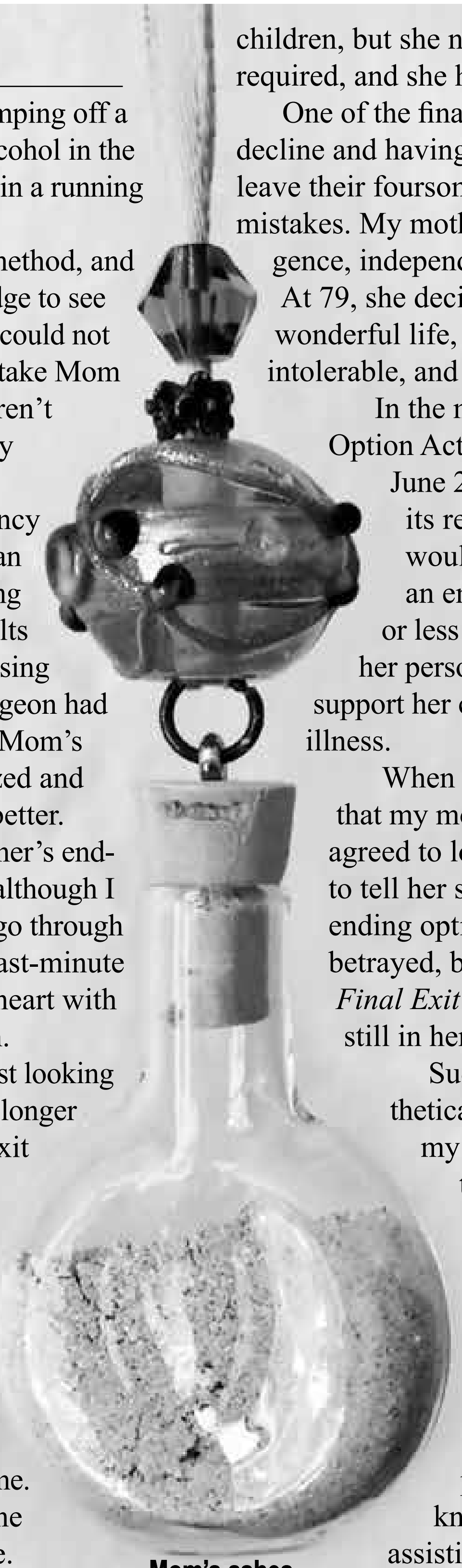
We favored the pill and alcohol method, and I called a friend with medical knowledge to see if they might have some advice. They could not help. Instead, they encouraged me to take Mom to the ER and tell the doctors we weren't leaving until they figured out why my mother was in so much pain.

At this fourth visit to the emergency room, doctors finally ordered a CT scan in the unlikely case there was something going on in the soft tissues. The results revealed an egg-sized hematoma pressing on her spine. It turned out that the surgeon had nicked a blood vessel when repairing Mom's vertebra. When the leak was cauterized and she awoke, she was already feeling better.

Through this experience, my mother's end-of-life values were reconfirmed, and although I continued to support her, I could not go through another wrenching and uneducated last-minute scramble. So, I had a frank heart-to-heart with her: She needed to have a better plan.

We did a web search together – first looking up the Hemlock Society. That was no longer active, but we found links to Final Exit Network. My mother became a member and bought the book, *Final Exit*, which we both read. She assembled a kit according to the handout (2011 version). Though we knew about FEN Exit Guides, she did not want them involved.

She was an independent woman and wouldn't have strangers in her home. The instructions seemed clear, and she was confident she had a plan in place.



Mom's ashes

• • •

Years went by, and Mom's health declined. She was diagnosed with Type 2 diabetes and struggled to control her unstable blood sugars. Her arthritis crippled her hands to the extent that she couldn't garden or even hold a book. She had been a volunteer for a project to clothe low-income children, but she no longer had the physical stamina required, and she had to quit.

One of the final straws was developing cognitive decline and having her bridge partners ask her to leave their foursome – she was making so many mistakes. My mother prided herself on her intelligence, independence, and ability to be of service. At 79, she decided she had lived a long and wonderful life, but now this limited existence was intolerable, and she was ready to leave.

In the meantime, California's End of Life Option Act had just gone into effect (the June 2016 version). We carefully studied its requirements. I doubted Mom would qualify, since she did not have an end-stage disease with a six-month or less life expectance. She was confident her personal doctor of over 30 years would support her claim that "old age" was a terminal illness.

When we went to visit him, he explained that my mother's request was his first, and he agreed to look into it. A week later, he had to tell her she wasn't eligible for that life-ending option. She was furious and felt betrayed, but I reminded her she had her *Final Exit* back-up plan – everything was still in her closet.

Suddenly this was real, not a hypothetical *what-if*. I started feeling sick to my stomach. Is she truly going to go through with it? Is she really ready? Am I? What would happen if this didn't work, and she ended up in a coma? I wouldn't put a pillow over my mother's face. And I didn't want to be directly involved with her death. I was the single parent of a teenager. I didn't know what the laws were regarding assisting a suicide, and we were both unwilling for me to go to jail.

I strongly encouraged Mom to apply to Final Exit Network's Exit Guide Program, but since she had been rejected by her beloved doctor, she was worried she wouldn't be accepted. *So, she was on her own.*

We reviewed the self-deliverance instructions

> ***I would go to her and be ‘surprised’ to find her body. Instead, I received a call in the morning: ‘I don’t know what happened – it didn’t work.’***

several more times. We were both clear that I would not be with her, but I did watch as my mom practiced.

She chose a date, and I visited the night before her planned exit, and we said our goodbyes.

The plan was that I’d be the “discovery” person. Mother would exit in the morning, and I would phone her in the afternoon like a normal check-in. Then, when she didn’t pick up after several calls, I would go to her and be “surprised” to find her body.

Mom’s hand – she died in her parents’ bed wearing her favorite flannel nightgown.

Instead, I received a call in the morning: “I don’t know what happened – it didn’t work,” Mom said.

I won’t go into detail, but it took her three more attempts in 10 days. She eventually reverted to non-FEN approaches before she finally died.

That week and a half was probably the most nerve wracking time in both our lives. While we were scared and unsure about the different methods she was trying, we also managed to joke a little. When the first try failed, we went out for her second “last meal.” Mom had diabetes, and she decided to order a milkshake, saying, “Maybe this will kill me!”

Before what became her final attempt, we agreed I wouldn’t stop by her house for a day and a half in case it took her that long to die. When she didn’t answer my call 36 hours later, I drove to her home, and she had died. She actually looked peaceful, so that was a huge relief.

While waiting for paramedics to arrive, I knew they would take her body, so I took some photos in case my family wanted to see (and they did).

• • •

I am so grateful my mother finally found the death she wanted – *but the process was terrifying.* After my son went to college and I retired, I decided to volunteer with FEN. I didn’t want others or their families to go through what we experienced.

I started first as an interviewer, then an Associate Guide, and currently I’m a Senior Guide.

From my training, I now know what went wrong with my mother’s first two attempts – user errors and obsolete instructions; she didn’t know the helium balloon tanks were being diluted with air.

If she’d been open to having trained Guides provide her with updated self-deliverance education, I am 100 percent convinced she would have died quickly the first time.

I wish there were an easy pill we could take when we felt ready. But this doesn’t exist.

If you or a loved one are looking at end-of-life options, especially if you don’t have access to Medical Aid in Dying where you live, I strongly encourage you to find out more about FEN’s Exit Guide Program. As a Guide, I have witnessed clients and their loved ones experience peace of mind knowing there’s a reliable plan in place.

My mother and I didn’t have this comfort, but now I’m making it up to both of us by educating others who seek end-of-life options.

Editor’s note: The author wishes to remain anonymous, to ensure privacy for clients, and notes that it is not illegal to be with someone who takes their own life. Also, FEN’s criteria for acceptance as an Exit Guide client is broader than for state-legalized medical aid in dying.

‘Smile’ is gone from Amazon

FEN is one of the thousands of US non-profits that will lose income with the decision to end the AmazonSmile donation program.

Amazon launched it in 2013, giving 0.5 percent of every purchase made by participating customers to the charity of their choosing.

The company recently announced that it would lay off 18,000 employees and cut other less profitable parts of its business.

Fiscal health for ‘23

– 1st outside audit adds to rosy picture –

From Executive Director Mary Ewert

As we move into 2023, I’m delighted to report that FEN’s financial position is solid. We accomplish much with our strong volunteer base and small group of three full-time staff, assisted by several consultants.

The response to our **2022 Annual Appeal** was robust, and we are grateful for the member support that we receive. FEN also received several large bequests in 2022, as well as grants from two foundations. With evidence of our strong financial position in hand, we will apply to several new grantors in 2023.

> ***Demand for Exit Guide Program services picked up noticeably in the second half of 2022, and a strong class of trainees has been stepping in to strengthen our volunteer team heading into 2023.***

Our first **external audit** resulted in a clean bill of financial health. We have taken this important step to assure our members and donors that their donations are used wisely.

Some of our members have questioned FEN’s ratings on charity-rating websites. Having audited financial statements to submit to those organizations will greatly increase our ratings and give potential donors and grantors the confidence they need to support FEN.

Demand for **Exit Guide Program** services picked up noticeably in the second half of 2022, and a strong class of trainees has been stepping in to strengthen our volunteer team heading into 2023.

The **database upgrade** I mentioned in the last issue is now underway. This will play a role in the foundation outreach program that our fundraising and communications consultants are developing, and enhance our interaction on social media.

In this issue, you will read about two new projects we are undertaking – the **Chosen Death Forum** and **End of Life Options Workshops**. The forum fills a need our members have expressed for venues where they can talk with like-minded people about their thoughts and experiences around choosing death. The workshops, still in the development stage, are geared to those thinking in advance about how they might want to peacefully exit, should that need arise.

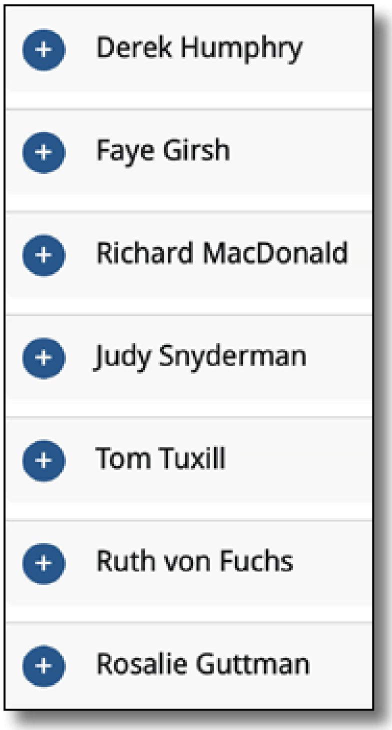
Remember to check out the newly developed **Founders and Heroes** page on the FEN website, accessed through the “About” tab. Many volunteer hours went into researching FEN’s founding, interviewing the founders, and putting together the stories of our *Founders and Heroes*. They are the pioneers who built the firm foundation upon which we stand today.

Besides our moving cover story (written by a FEN Exit Guide), this magazine has two other intimate stories about EOL exits. Both got wide media coverage – and each was tragic.

We continue to look for personal accounts related to members’ experiences. Send your stories and ideas to info@finalexitnetwork.org.

FEN is growing and flourishing. I’m confident that 2023 holds many good things for us.

As always, thank you for your ongoing support.



Derek Humphry
Faye Girsh
Richard MacDonald
Judy Snyderman
Tom Tuxill
Ruth von Fuchs
Rosalie Guttman

Our charter Founders and Heroes, from the FEN website.

Final Exit NETWORK

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QUARTERLY MAGAZINE

Jay Niver

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.

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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.

States waste little time tackling MAiD

By Jay Niver, FEN Editor

Before the calendar even flipped to February, a flurry of RTD legislative activity was underway in statehouses across the country. And, increasingly, the initiatives go beyond merely passing new legislation, but also seek to modify and improve existing laws.

After Oregon's ground-breaking 1997 Death With Dignity Act, states were basically content to follow its template. But the plethora of "safeguards" built into that model has proven to be barriers to access for many who want the option of Medical Aid in Dying.

Here's part of what's happening already in 2023.

- Bills to legalize MAiD are introduced in Massachusetts, New York, Rhode Island, Connecticut, Virginia, Arizona, and Indiana.

Rhode Island and the Hoosier State are late-comers to the effort, both having filed their first bills last year. Virginia is making a fourth attempt since 2019. Others, like Connecticut and Arizona, had their initial filings in 1995 and 2003, respectively.

New York has come within a whisker of passing MAiD, and last year more than 3,600 letters were sent to lawmakers in support of it.

- Two states with MAiD have bills to eliminate a residency requirement: Oregon and Vermont. Oregon agreed last year that patients not living there could receive MAiD, and legislators are being asked to remove that provision from the current law.

Vermont, since passing its law in 2013, has liberalized and opened access between 2015 and 2022.

- Washington State continues efforts to increase its MAiD access after a failed attempt in 2021. This year's bill would let registered nurse practitioners and some physician assistants make a terminal diagnosis.

- A bill in Hawaii follows a failure two years ago to reduce or eliminate the waiting period, and allow some nurses to be part of the applicant screening process.

Huck DeVenzio

In praise of a true original

Sometimes life cheats us out of wondrous things we wish we could have known, loved, and experienced. Occasionally it's a very special person we barely met, or who left us too soon. Charles "Huck" DeVenzio was one such person, a longtime FEN volunteer who touched so many in all he did.

Huck edited this magazine from 2016 until poor health forced him to step aside in 2019. He joined FEN in 2011, but best friend Brenda Heindl has his worn Hemlock Society membership card for 1990-91. She said Huck never considered a planned exit for himself, but fervently believed everyone should have the option.

If you didn't really know him, read the obituary he wrote himself. It eloquently hints at what you missed.

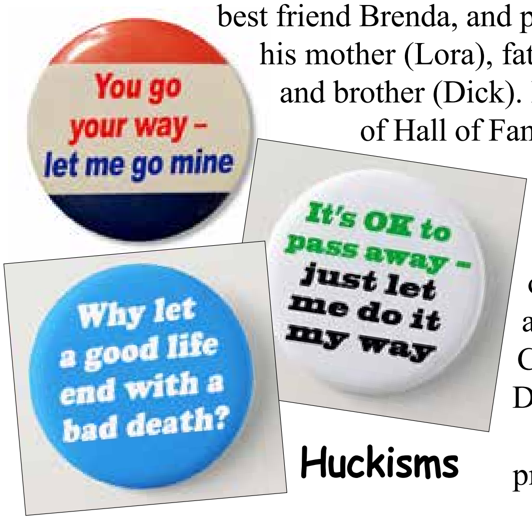
– Jay Niver, Editor

Charles (Huck) DeVenzio
January 20, 1947 – December 6, 2022

By Huck DeVenzio

After 75 years of unnecessary or unconscious risk-taking, Huck DeVenzio died (on December 6) as a result of Parkinson's disease, an ailment he was said to have suffered from or, at least, heard of. Known for his cheesy Christmas cards and fondness for places serving fruity rumbdrinks, he has lived primarily in Springdale, PA; Pittsburgh, PA; Smyrna, GA; and most recently, Germantown, TN.

He is survived by brother Dave, sister-in-law Amy, sister Anne, three nieces (Emily, Lora, Becca), and best friend Brenda, and pre-deceased by his mother (Lora), father (Chuck), and brother (Dick). He was the son of Hall of Fame High School basketball coach Chuck and the brother of All American and Roundball Classic MVP Dick.



Huckisms

A traveler and practically a sportsman, Huck was a certified SCUBA diver, rafted the Grand Canyon, was in the ring with a professional wrestler, went to Kentucky Derby and flyball competition, Rhythmic Gymnastics and Paso Fino national championships.

A cultural icon having yodeled with a Swiss folk group, performed on stage with Italian opera singers, set an international aviation speed record, sky dove, hang glided, got one vote for second-team All American basketball, played one intercollegiate tiddlywinks match, attended a World Series game, raced an America's Cup yacht, played one note on Atlanta's Fox Theatre organ, wrote comedy routine for Michael Keaton, was applauded by audience of Luxor Theater.

Edited six books, produced half-hour TV show. His creative output culminated with his 2022 Halloween costume, cow-abunga.

Marketing manager, preserved lumber. Earned BS he never used from Cornell, earned BA he never used from Pitt. Got robbed by polite muggers in Venezuela. Spent a night in a locked Australian airport terminal. Aka Huck Q.

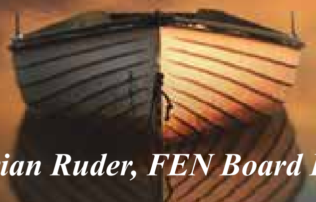
Rather than sending flowers or gifts, please do something nice for friends, family, or a stranger.

Final Exit Network remembers Huck

- *His leadership on our communications and media strategies left a lasting legacy at FEN – and those who worked with him treasured his droll sense of humor, enthusiasm, and commitment.* **– Janis Landis, FEN board**
- *Huck's warm, open-hearted presence let me feel immediately comfortable with him. I remember him for his humble introspection, genuine interest in other people, and ability to balance painful realities with good-natured humor and perspective.* **– Lowrey Brown, client services director**

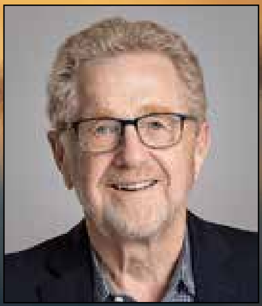
Peace of Mind

FEN in-person workshops coming



By Brian Ruder, FEN Board President

In 1991, when Derek Humphry published his book, *Final Exit,* it was on the *New York Times* best seller list for over 15 weeks, not because people wanted to die, but rather because they wanted information on how to hasten their death, should the need present itself. It gave them a certain peace of mind.



Brian Ruder

As a Senior Exit Guide, I find that one of the important and powerful elements of Final Exit Network (FEN) services is providing peace of mind to our clients. When they have the information and equipment for a safe, legal, effective way to die, they gain a wonderful sense of relief.

Today, more than ever, I believe our members and supporters would like to have a similar peace of mind, of knowing they have some control over their dying and death process, though they are not planning to end their lives in the near future.

FEN is developing a workshop program for members in 2023-24 that we hope will address this desire. We have named them Are You Ready? The first pilot workshop is tentatively planned for April.

The two- to three-hour workshop will focus on where FEN fits into the right-to-die movement, how to better position yourself for choice in dying, the tools that FEN uses for its services, and the things you need to plan for a safe, legal death.

The workshops will also provide a brief overview of other legal, safe and peaceful options for hastening death. Initial workshops will be limited to 25-30 members who live within a comfortable drive. This will allow participants an opportunity to get questions answered in a friendly setting, and for us to learn what is most important to our members.

We are also considering holding some workshops in member homes. We plan to offer a few workshops in 2023 and to expand the program in 2024, if there is sufficient interest.

FEN can provide these workshops thanks to a grant we received from the William H. Donner Foundation. We will continue to reach out to foundations for financial support for education and research projects.

Keep an eye on your email and our website for future information. Please be patient, as we cannot schedule workshops everywhere at once.

If you would like one in your area, please email workshop@finalexitnetwork.org. That would help us gauge the level of interest geographically.

12 from FEN gain world view at Federation conference

Mary Ewert and Brian Ruder were among 12 FEN members attending the 2022 World Federation of Right to Die Societies meeting held in Toronto Nov. 3-6.

There were 170 registered to attend the two-day meeting, including Faye Girsh, Ruth von Fuchs, and leading RTD bioethicist Thaddeus Pope.

“Many of the 25 work sessions addressed Canadian activities, but there were plenty of interesting presentations from around the world,” Brian said.

Among them were Mary’s program on FEN research and Thad’s topic of Voluntarily Stopping Eating and Drinking (VSED, on which he’s an expert).

For an international perspective, over 4.5 percent of all Netherlands deaths are hastened; in Switzerland, it’s 1.8 percent; in Oregon (after 25 years), it is less than 1/2 of 1 percent who use medical aid in dying.

Canada’s progressive MAiD law does not require a terminal diagnosis, and this year advocates will be working on a track to accommodate mental illness.

Husband grieves: MAiD didn't help

TONI HAD TO DIE ALONE

By Peter Haley, FEN Member
Seattle, January 2022

My beloved wife of 27 years had to die alone.

It shouldn't have been that way. We both wanted Toni's suffering to end with her dying peacefully in my arms, but Washington State's supposedly enlightened "Death with Dignity" law wouldn't let her.

In spite of first-class medical care, her disease – one of the many variants of ALS – was slowly grinding her down.

Toni's primary identity was not as an attorney, wife, or prankster nonpareil, but as a distance runner. She enthusiastically, and sometimes doggedly, ran every day for 30 years, only missing a couple of days due to the flu. So it was brutally ironic that the first thing the disease took was her legs' ability to support her.

We knew what lay ahead. Her brother had recently died of the same disease and she didn't want a repeat of the prolonged misery that he and his family endured.

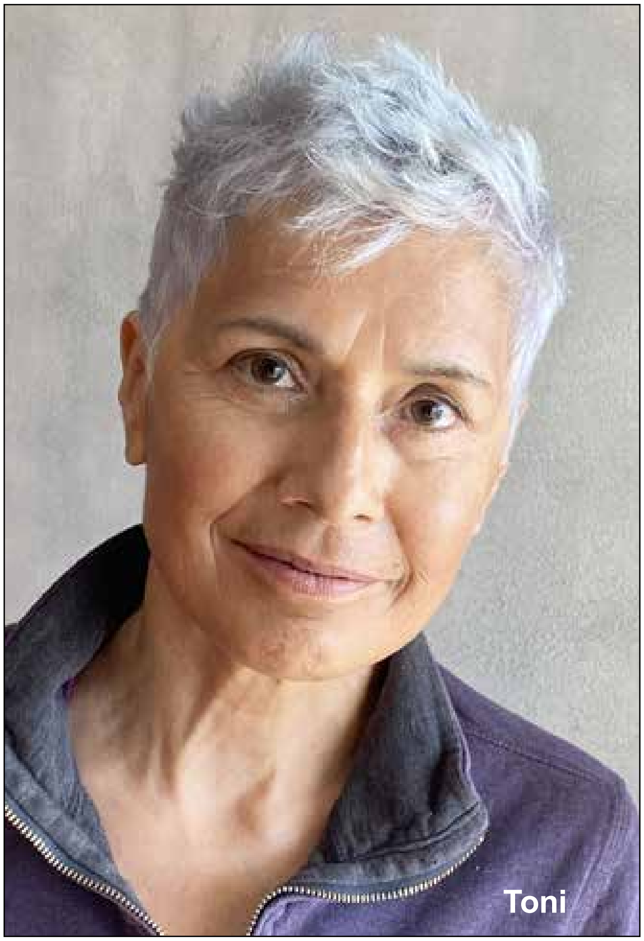
Our current law says that to get aid in dying a patient must have a diagnosis of natural death within six months. But because her disease was slow and inexorable, it would mean more years of suffering before she could qualify for medically aided death.

Finally, after about eight years of decline, the force and bewildering variety of her symptoms overwhelmed her uncommon ability to extract every last drop of fun out of living. Her effervescence still shined on occasion, but less and less. We knew that "Wild Thing" (my pet name for her) would have to figure out how to end it all.

And not merely how to do it. Because she didn't qualify for medical aid in dying, she would have to do it alone.

I hate this fact.

It's bad enough that nature deprived us of an expected 25 more years of love, but it breaks my heart that our poorly formulated laws prevented me, and everyone else, from giving her aid and comfort during the planning and carrying it out. If it appeared that I had assisted in any way, I would be in legal jeopardy.


Toni

She had to face these grim tasks alone.

In recent years we talked about everything except how and when she would die. For my protection, she wouldn't let me know the specifics. All I knew was that in a year or three she would end her life somehow, at some time.

I now know that with information from Final Exit Network she was able to select a method and buy the materials. Aware of the dangers of botching the job, she even sent a sample of the chemical to a lab to confirm that it was the right stuff.

But how does a person decide when the pain is persistent enough, when the happiness is rare enough, to actually do it? The story of the frog in slowly heating water comes to mind. If anybody could resolve to do it without discussing plans with anyone, and then accomplish it, it would be Toni.

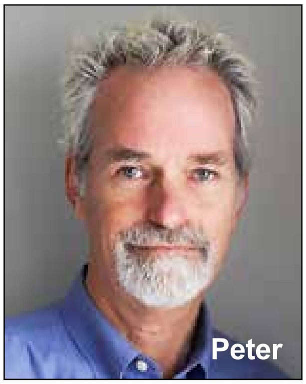
I am fiercely proud of her bravery and force of will.

But I'm also angry because we, as citizens in charge of our laws, have badly failed her and many others. We need to improve these laws as Canada's Parliament did in 2016.

We should drop the six-month requirement and keep the requirements that a patient have a grievous and irremediable medical condition, an advanced state of decline, and unbearable suffering from the illness. And we should keep the more general safeguards regarding the patient's age, mental health, informed consent, unacceptable motives, pressure from family or others, etc.

If Washington had such a law, we and our loved ones would have come together for a wonderful and tearful good-bye, rather than attend a memorial service. And Toni's last moments would have been in my warm, loving embrace.

[Peter Haley is a lifelong Northwesterner and retired newspaper photographer.]



Feb. 1 all-member online meeting addressed questions

FEN leaders brought more than 200 members up to date on what's happening and answered their questions in a Zoom meeting Feb. 1.

It was a chance for Deborah Alecson to talk about the new, monthly *Chosen Death Forum* that started last fall (story on page 11). It's similar to the familiar Death Cafes that are long-established around the US.

Board President Brian Ruder told attendees how the new, in-person *Are You Ready?* workshops will bring "peace of mind" (story on page 7).

Lowrey Brown, client services director, refreshed everyone on the Exit Guide Program and said client numbers bounced back in the fourth quarter last year. She also said another training for Guides will not likely be held before spring of 2024.

ED Mary Ewert reported that FEN's first outside audit revealed no red flags, and that should help the organization garner better ratings by groups that rank nonprofit agencies.

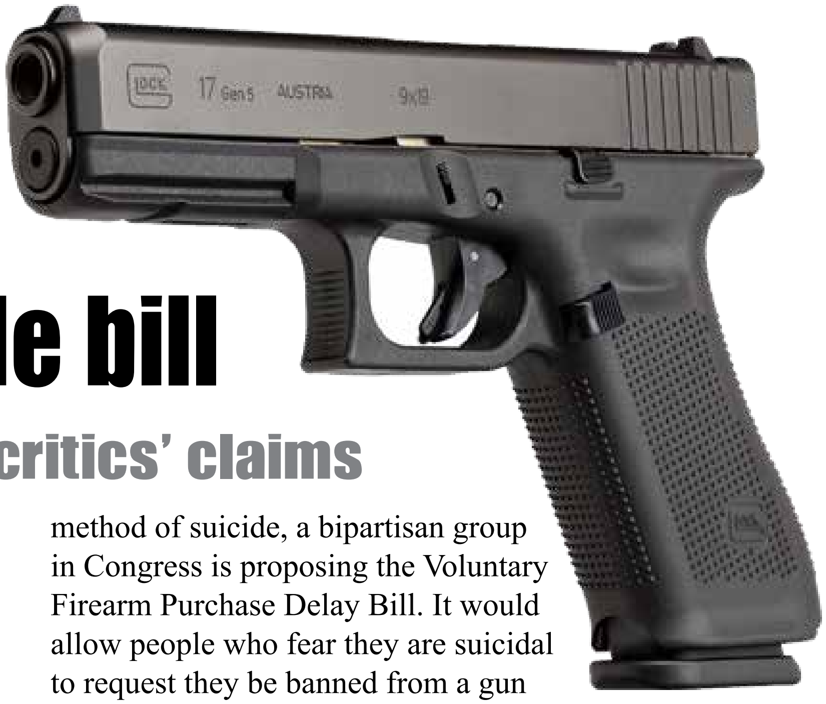
FEN Founders & Heroes

The vision for Final Exit Network began at a hotel in Chicago on August 13 and 14, 2004. The founders were a group of 10 activists, motivated by compassion and personal experience. They were determined to provide a way for people – if they were suffering from intolerable circumstances – to have a dignified death. The heroes joined the founders and helped to make Final Exit Network what it is today. Read their inspiring stories on FEN's website (finalexitnetwork.org).

Some of the FEN pioneers include Derek Humphry, Faye Girsh, Dr. Tom Tuxill, Judy Snyderman, Dr. Richard MacDonald, and Ruth von Fuchs.

Toronto Star

2nd Amendment zealots would kill smart suicide bill



MAiD saves lives, despite critics' claims

By Janis Landis, FEN Board Member

Critics of the right-to-die movement believe that it "causes" suicides and that suicide is always wrong. Obviously, at FEN we believe that suicide under certain circumstances (and with careful guidelines) is sometimes the best available option.

But what our critics often don't take into account is that a careful process such as FEN's can, and does, save lives.

> ***For these elected representatives, suicide is just the price emotionally distressed people will have to pay to protect the Second Amendment.***

Many of our clients get sufficient peace of mind just by knowing they are approved, and that they can proceed if their situation becomes unbearable. That knowledge alone is sufficient to give them the strength to fight on and live their remaining time fully and without fear.

A second, less widely known way we save lives is through the process of discussions with applicants we turn down. The chair of our Medical Evaluation Committee personally contacts every applicant who is not accepted.

Interestingly, he is often able to reassure the individual that their illness is not as dire as imagined, and they have many helpful medical interventions. This often comes as a welcome surprise to applicants who are overwhelmed by an initial diagnosis and fear that their own doctor's optimism is unfounded.

Finally, and most importantly, the process itself weeds out an impetuous suicide based on temporary emotional stress (e.g., job loss, divorce, family death). These impulsive suicides are the real tragedy, and why the suicide-prevention hotline is on our website.

And here's where the hypocrisy of some of our most vocal critics becomes clear.

The overwhelming majority of impulse suicides are carried out with guns. To tackle this widely used method of suicide, a bipartisan group in Congress is proposing the Voluntary Firearm Purchase Delay Bill. It would allow people who fear they are suicidal to request they be banned from a gun purchase. They can revoke it themselves without any approval from anyone.

In other words, only the individual can request the ban, and they have complete control over revoking it.

The bill would help individuals suffering from depression and other mental disorders by giving them a buffer of time, if they choose. They can reach out to their therapist or family for help, because the immediate ability to act on their suicidal impulses is not available.

This is common-sense legislation, something both RTD organizations and their opponents should completely agree upon.

And yet, this legislation is being opposed by some in Congress as "another attack on the Second Amendment." Not surprisingly, these critics are also vehemently opposed to rational suicide for those suffering irremediably from disease or illness.

"Do we really need a federal statute to permit a person to volunteer to give up their fundamental liberty?" asked one member. "That's what this bill does. Mental health is important, we all understand that, especially as it relates to suicide, but this …

"I mean, really? This is what we're going to do?"

For these elected officials, suicide is just the price emotionally distressed people will have to pay to protect the Second Amendment – while data tell us that 65 people a day will die by firearm suicide.

New FEN forum models national Zoom Death Cafe


Celebrating a life after death is easier if the exit is compassionate, peaceful, and planned.

By Jim Van Buskirk, FEN Member

Chosen Death Forum (CDF), a new project of Final Exit Network, has successfully launched.

All FEN members have by now received an invitation to join this informal monthly Zoom discussion group, and some members have taken advantage by attending multiple times.

After several months of trial and error, the program seems to be meeting the need as envisioned by its co-creators, which was to provide a safe space to discuss topics surrounding end-of-life options

It is based on the popular Death Cafe model, now flourishing for years around the world. But not everyone has a “Cafe” nearby, and the convenience and optional anonymity of online participation appeals to many.

CDF is an open forum to discuss with like-minded people ideas, feelings, and concerns regarding choosing one’s own time of death, either through medical aid in dying (MAiD), voluntarily stopping eating and drinking (VSED), or other non-medical means.

This forum is also for those whose loved ones are contemplating EOL options. Because of the sensitive and sometimes stigmatized nature of this topic, special care is taken to offer a safe space and to keep the conversation focused.

There is no discussion of technical aspects of self-deliverance, including equipment or drugs.

CDF is open to people 18 or older, and it is not a forum for those in a reactive state who are suicidal. These individuals should reach out to the National Suicide Prevention Lifeline (988).

Also, FEN clients of the Exit Guide Program are not eligible to participate.

Originally proposed by regional coordinators Deborah Alecson and myself, the project has been ably supported by ED Mary Ewert and Exit Guides Lily Chambers and Mary Ellen Bates.

After initial introductions by Deborah and Jim, depending on the size of the group, participants are randomly assigned into break-out rooms.

Facilitators have determined that the ideal number for intimate discussion is between eight and 12 people, and at least one FEN volunteer holds the space in each break-out room.

The guidelines, which are posted and read before each meeting, include:

- Specific aspects of how to exit, like sources for drugs or equipment, are never a topic.
- No solicitation of any kind. CDF is not a forum for requesting FEN services.
- CDF is a discussion group. Sharing personal experiences can often further a conversation, but venting does not.
- What is shared will remain confidential among the participants. But the Zoom meeting will be recorded.

“The people who have signed up are extremely introspective, thoughtful, knowledgeable and have a sense of humor,” said Alecson. Topics raised thus far have included language (e.g., “committed suicide”), discretion (with whom is it safe to discuss intentions), and specific interest in the combination of VSED, cognitive decline, and Advance Directives.

There was discussion about “the conversation” with family members and the difficulties (some participants talked about trying to talk to their children about their own wishes to choose their time to die); the benefits of writing one’s own obituary; and MAiD.

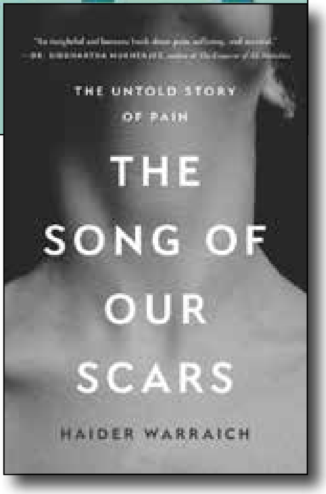
A couple of folks living in states with legal MAiD spoke about the issues with the program (lack of doctors participating, problems getting the prescribed dose).

We encourage you to check out this new program!

More Good Endings

Book & Movie Reviews by Jim Van Buskirk

Haider Warraich, MD



Three Titles – 2017-2022

Many books about end-of-life options, including – or especially – those by physicians, shy away from discussing hastened deaths, if at a hospital, hospice, or home. Refreshingly, this is not at all the case with Dr. Warraich's thoughtful and thought-provoking book *Modern Death: How Medicine Changed The End Of Life* (2017).

Specifically, in his chapter "When the plug is pulled," he carefully disambiguates between the controversial terminology of physician-assisted suicide (aka Medical Aid in Dying), terminal sedation, and euthanasia. He ends with this practical approach:

"The deaths we die cannot be truly modern until we bring the subject of death within the pale of conversation and start having calm, educated conversations about it in classrooms, bars, restaurants, backyards, and, of course, in the clinic."

In his 2019 book – *State of the Heart: Exploring The History, Science, and Future of Cardiac Disease* – the prolific author and physician, with his customary humanity and humility, focuses on the heart. He investigates the organ, chronicles cardiac disease, and describes the recent developments, including statins, left ventricular assist device (LVAD), and cardiopulmonary resuscitation (CPR), as well as hope for future biomedical innovations.

He also realistically emphasizes current limits, emphasizing that it is hard for physicians to know when to stop intervening, and what that means for patients. "It means that patients with heart disease are more likely to die in a hospital than at home – and to die at home is what the vast majority of patients want – than are patients with diseases such as cancer. It means that palliative care, known to improve quality of life in terminally ill patients, is grossly underused in patients with heart disease."

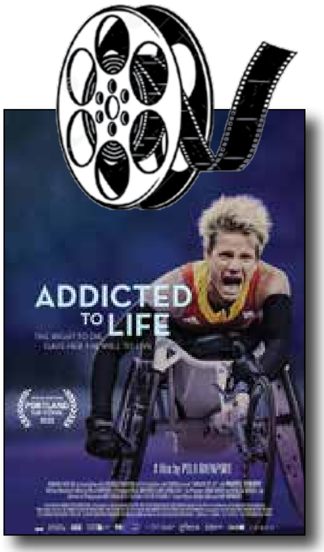
Dr. Warraich's roles as a physician and professor, combined with his personal experience of living with debilitating chronic pain, give him excellent credentials to tackle the complicated topic of pain.

The informative and accessible 2022 narrative of *The Song of Our Scars: The Untold Story of Pain* includes detailed descriptions of recent distinctions between chronic and acute pain, the use of opium in the 1890s contrasted with the opioid crisis of the 1990s, and the effects of race, class, and gender on patient-physician relations.

Because unremitting pain is often a reason people consider hastening their deaths, coupled with the fact that they can no longer get the opiates that had been prescribed for years, this book offers a welcome validation.

Together, and separately, these three titles add greatly to our understanding of the medical profession's ever-evolving relationship to pain and suffering – and death and dying.

Addicted to Life



2022 – 86 minutes

'The right to die has given her the will to win.'

The film's vital tagline succinctly captures Belgian Paralympic champion Marieke Vervoort's inspirational story.

The documentary begins when, after winning medals at the 2016 Rio Paralympics, she announces her intention to use Belgium's euthanasia law. (Euthanasia, literally "good death," is the term used in Belgium for legal medical aid in dying.)

Diagnosed at age 14 with reflex sympathetic dystrophy, an incurable degenerative disease of the muscles and spine, Vervoort endured years of severe pain, paralysis in her legs, and epileptic seizures. As the frequency of her symptoms became more frequent and more severe, the vivacious athlete wrestled with exactly when is the right time to take advantage of Belgium's liberal law on physician-assisted suicide.

"You have to live day-by-day and enjoy the little moments. When the day comes – when I have more bad days than good days – I have my euthanasia papers. But the time is not there yet." Vervoort (always accompanied by her beloved assistance dog, Zenn) convinces her family and friends that having control is what she needs to stay alive.

She appreciates the support of her personal physician, Dr. Wim Distelmans, chairman of the Federal Euthanasia Commission of Belgium.

Vervoort continues to live life to the max, addicted to the adrenaline and adventure of international travel, intense competition, media attention, and a wildly physical bucket list (indoor skydiving, bungee jumping).

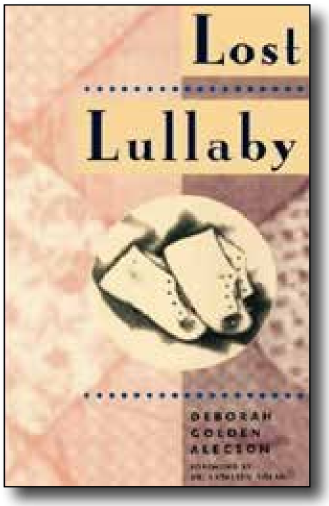
She was euthanized in October of 2019.

Renowned husband-and-wife filmmakers Pola Rapaport and Wolfgang Held achieved incredibly intimate access to the very private challenges of this charismatic public figure, whose *joie de vivre* attracts fans, girlfriends, celebrities, and other people with disabilities. She even tries to control how the film should end.

The film had its US premiere at the Portland Film Festival where it won "Best of Women's Voices." It was released Feb. 1 in Belgian cinemas.

Deborah Alecson

Two Titles – 2014



"Like every couple that wants to have a child, we hoped for a healthy baby whom we would watch unfold over the months and years into a delightful person in love with the world."

With this seemingly innocuous first sentence of *Lost Lullaby*, Deborah Alecson's anguishing journey begins. Due to a medical mishap, the full-term baby, named Andrea, was deprived of oxygen in the womb for an indeterminate amount of time, resuscitated into life, and kept alive on machines, perhaps indefinitely, despite massive irreversible brain damage.

With clarity and conviction, Alecson charts the tragic trajectory, documenting every twist and turn in their road to hell. Deborah's initiation into motherhood brought two unexpected desires: the need to nurture her baby and the hope that she would die.

The hospital's neonatal intensive care unit became the site of her supreme conflict. Repeatedly traumatized by the insensitivity of the personnel around them, Deborah and her devoted husband, Lowell, fight to obtain power over their child's destiny.

While navigating her own complex emotions, she must deal with those of Lowell and their family and friends, as well as to educate herself about medical technology, family rights, and legal ambiguities.

Focused on the moral and spiritual aspects of the tragic situation, they must also reluctantly acknowledge legal issues. Having a lawyer sue the hospital, midwife, and obstetrician for alleged malpractice complicated the already torturous waters. Keeping Andrea alive would likely result in a potentially large monetary settlement, while her death would mean a negligible one.

The couple, navigating the medical and legal constraints that are misguided, hypocritical and cruel, ultimately achieve amazing compassion and wisdom. Alecson's remarkable ability to rise to the occasion and to share it so intimately is admirable.

The couple's cautionary tale reminds readers how vitally important it is to be aware of our basic human rights and those of our loved ones. Alecson certainly achieves her desired goal: "It is my hope that Andrea's story will make these intricate issues human, and will convince readers that death can and should be welcomed when the alternative is a living hell."

Regretably, Alecson's relationship with death reignited a decade later, when her "best friend and lover," Lowell, 52, died of pancreatic cancer. At the urging of medical professionals, he initially tried chemotherapy "even though his cancer was incurable and the treatments experimental and lethal." In *We Are So Lightly Here*: *A Story About Conscious Dying,* Alecson's willingness to share intimate details of the roller coaster ride – including journal entries, poems, and excerpts from *The Tibetan Book of the Dead* – afford the reader an immediacy to this glimpse into seldom-seen territory.

Music is vital to the journey, both for Lowell (a gifted musician and teacher), and their son, Skyler, 9. With Deborah's support, Lowell was able to conduct his high school choral students one last time.

Alecson is unafraid to share her frequent anger and frustration: "Families don't talk about the most important things in life!" And, she continually reminds herself: "All that I have to do is love him."

FEN blog nears 5-year birthday

Thriving forum approaches 95,000 visits since May 2018

By Jay Niver, FEN Editor

Analytics researchers who are supposed to know such things say that an average reader spends 37 seconds reading a blog post. What's more, 43 percent skim through the content, rather than read it thoroughly.

Folks who read FEN's *Good Death Society Blog* obviously are not "average" – they spend more than three minutes on the site.

This online presence makes FEN 'a significant voice in the right-to-die movement.'

"That's sufficient time to at least thoroughly read an article," says Gary Wederspahn, FEN board member who – along with Lamar Hankins – gave birth to the blog in May of 2018. "It's an indication of exceptional reader interest, which also has been demonstrated by more than 1,300 comments to date."

Wederspahn is back on duty, monitoring the blog for months now along with Melanie Raine. The forum has had additional editors, and all have stayed busy with other FEN projects after passing the baton.

Gary assembled a detailed report on the blog to present to the board in late December. The last update had been in June of 2020.

Maybe the reason *Good Death Society* visitors take time to ingest content is that they're treated to a wide range of impressive authors who post on the site. By the end of last year, 101 different contributors had written for the blog, including 27 FEN members.

"Our authors include prominent leaders of the right-to-die/death-with-dignity movement, journalists, end-of-life care professionals, ministers, counselors, lawyers, and physicians," Wederspahn says. "Their variety of backgrounds, viewpoints, and information contributes much to our goal of positioning the blog as a trusted and respected public forum."

It comes back to *the company you keep,* he adds: "The willingness of notable writers to have their names and reputations associated with us implies their endorsement of our mission and values. That increases FEN's legitimacy in the eyes of the public."

By any metric, the blog's growth and success – now 60 visits daily and 525 subscribers – bode well for Final Exit Network. According to Gary, this online presence makes FEN "a significant voice in the right-to-die movement."

Keeping content fresh frequently is one key to achieving in the blogosphere. "By the time this magazine goes to press," Gary says, "we'll have posted a new article for more than 280 straight weeks."

Gaining exposure for Final Exit Network and the blog's contributors extends beyond the initial posting of an article. It's not unusual for an author to repost what they wrote on their own website, which brings a secondary audience to the piece and where it originated.

In addition, members of the FEN Speakers Bureau reference the blog, and that brings a new set of potential readers and FEN followers.

Social marketing research says 68.5 percent of people think blogs add credibility to an online site.

THE BACK PAGE

A COMPENDIUM OF RIGHT-TO-DIE WORLD NEWS

United States

New Mexico – Mark Lacy, a New Mexico doctor, and the national group Christian Medical and Dental Associations, filed suit in December against the state's MAiD law, passed in 2021.

As in California, the New Mexico law says no physician can be forced to participate in a life-hastening procedure – but defining "participate" is the challenge. Lacy claims he should not have to refer a patient to a willing doctor. In addition, there is paperwork he must file related to any MAiD case, even when he refuses to take part.

"How hard is it for a doctor to tell a patient, 'I don't believe suicide is the answer and I can't be a part of it, but you have a right to know your options and I can refer you to another physician,'" countered an editorial in the *Albuquerque Journal*.

Portugal

A Portuguese court has rejected its parliament's attempt to introduce euthanasia into the country, pointing to the "intolerable vagueness" of the proposed legislation.

The court rejected a law in February to introduce euthanasia for the second time, sending the measure back to parliament, saying it failed to properly define "suffering of great intensity" that might be grounds for a "medically assisted death."

Parliament will have to redraft the proposals and submit them for approval to the president, who had previously referred them to the Constitutional Court.

One parliamentarian in favor of assisted dying, Isabel Moreira, claimed the issue was only a "semantic problem."

Canada

Plans to allow people with mental illness to access medically assisted death were postponed in December amid concern that the country's healthcare system is not prepared to handle the complicated cases.

Canada's liberal RTD legislation was set to broaden March 17 to include people whose sole conditions are mental disorders. In February, Justice Minister David Lametti introduced a bill in parliament seeking a one-year extension to 2024 for such an inclusion. He expressed confidence it would get broad support.

"It will allow the completion of in-depth studies of the risks and complexities associated with providing MAiD to individuals whose sole underlying condition is mental illness," he added. "We want to be prudent. We want to move in a step-by-step way so that we don't make mistakes."

Psychiatrists have spoken out recently about a lack of preparedness within the healthcare system, and media reports have highlighted controversial cases, increasingly polarizing the issue.

India

In late January, a five-judge Bench of the Supreme Court agreed to significantly ease the procedure for passive euthanasia by altering existing guidelines for living wills, as laid down in a 2018 judgment that allowed "mercy killing."

At the same time, the Bench also removed the condition that required the person to get a magistrate's approval for withdrawal or withholding of life support during terminal illness.

Now, the documents for passive euthanasia would be signed by the executor of the "living will." However, the document must be signed in front of the two attesting witnesses, whom the court ruled should be independent. Also, the living will should be attested before a notary.

South Australia

Laws allowing voluntary assisted dying took effect Jan. 30. After 16 failed attempts in 26 years, legislation passed the South Australian Parliament in 2021, allowing for a voluntary assisted dying (VAD) scheme to be established.

The legislation outlines how, and for what reasons, voluntary assisted dying can be made available to people at the end of their life.

Psychiatrist Melanie Turner has been appointed as the first presiding member of the SA Voluntary Assisted Dying Review Board, which will oversee the landmark scheme while collecting patient data and community feedback. Dr. Turner said she was confident the scheme was a "compassionate" system, with enough checks and balances to help eligible people understand, and use, the option.

The law includes many safeguards to ensure only eligible people can access VAD, and to protect vulnerable people from coercion, abuse, and exploitation, according to Dr. Turner.

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Tragedy exposes need for Fla. MAiD

Wife is charged after mercy killing

By Jay Niver, FEN Editor

Ellen Gilland

A 76-year-old Florida woman is facing a murder charge after a murder-suicide pact with her terminally ill husband went horribly wrong.

Police say Ellen Gilland and her husband, Jerry, 77, planned three weeks in advance to end his suffering if his health took a turn for the worse.

It did. So, on Saturday, Jan. 21, she fatally shot him in a Daytona Beach hospital. The original plan was for him to pull the trigger, but he didn't have the strength. Ellen did it for him, then according to plan, was to take her own life – but couldn't go through with it.

A standoff with police and hostage negotiators lasted more than three hours before she was taken into custody. Gilland never threatened or pointed the gun at anyone. She was arraigned on multiple charges the following day.

Ellen and Jerry could not choose Medical Aid in Dying. Florida has no such option for terminally ill, suffering people. So, they did what too many desperate couples are forced to do: *They planned around a firearm.*

Their tragedy is reigniting discussion across the country about the need for MAiD. *LA Times* columnist Nicholas Goldberg weighed in quickly:

"In California, Jerry Gilland probably could have gotten the certification of two doctors that he had only half a year left, and he could have been allowed to end his life at home with medication – without the mess, the drama or the murder charges," he opined. "What's the point of charging Ellen Gilland with first-degree murder?"

In the Sunshine State, the Florida End of Life Options Act is being proposed by Florida Death With Dignity. Tony Ray, president and founder of the organization, said that as of January, "We have contacted all the legislators to educate them or their aides, and several said they would support this bill."

Ray added: "We have a Senator who said she will sponsor our bill in the March legislative session *if* we have a sponsor in the House."

Columnist Goldberg is a right-to-die advocate, but he did not approve of Gilland's actions. Still, he wrote: "It is exactly the kind of thing that happens in a society where suffering or dying people can't legally end their own lives when they decide it's time."

Meanwhile, as this publication went to press, Gilland remained in jail without bond. In similar cases, prosecutors have allowed defendants to plead to lesser charges.

Bodycam footage shows officers outside of the room where Ellen Gilland fatally shot her dying husband – at his request.