FinalExit NETWORK

The Human Right To A Death With Dignity

IN THIS ISSUE

VOL 22 • NO 2 SPRING 2023

> ‘It was difficult watching two people who loved each other struggle with the decision of when to die.’

Living, loving & leaving – with ALZHEIMER'S

By Brian Ruder, FEN Board President

"Michelle" was beautiful in every sense of the word. She was in her late 60s and radiated happiness and love for "Ron," her husband of many years.

When FEN Exit Guides first stepped into their home in October of 2019, we saw a world of beautiful art from Michelle's life. She and Ron were both artists, and their home and yard were a gallery for their work.

As we sat talking to them, I had a sense of peace and tranquility. I realized they were taking Michelle's diagnosis of Alzheimer's in stride. Her mother had died of it, and she had seen Mom suffer for years. It felt right that Michelle, who was in a very early stage of Alzheimer's, did not want to suffer like her mother. But she did not want to die any sooner than she had to.

We also learned that Ron had a family history of heart disease that made him worry a little about being able to take care of his wife in the future.

The hard part of living with Alzheimer's is that the changes each day can be very gradual and easy to accept as the new "normal." At the end, Michelle said her brain was no longer able to process things as it had a few years ago. She could not read or write anything of consequence. She could no longer keep a journal. But she could still enjoy her time with Ron – and he with her.

They especially enjoyed cooking and eating together.

Michelle painted this self-portrait of how it felt to be shackled by Alzheimer's.

It was difficult watching two people who loved each other struggle with the decision of when to die. Michelle did not want to die

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Renew your membership online: www.finalexitnetwork.org

LEAVING

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leaving Ron alone – and Ron did not want Michelle to die, because he loved being with her and taking care of her. But they both knew that, over time, she would lose the competence to make decisions, and her daily care needs would become more difficult.

Ron's health issues added more uncertainty – but they both wanted to put off the decision as long as possible. So, for them, the question was: Should they hasten death before losing capacity, or wait and use FEN's Supplemental Advance Directive for Dementia Care (SADD). While it was clearly Michelle's decision, their love for each other – and wanting to share their last days as long as possible – made her decision difficult beyond words.

One day early this year, I got a call from Ron telling me that Michelle had awakened that morning feeling the time had come to end her life. When we arrived, Michelle told us that in the last few months, she had been getting very tired during the day and had to take naps, or at least sit down a couple of times to rest.

Michelle felt her window of opportunity was closing. She felt her tired spells were a sign of that. She had made the final decision and was ready to end her suffering.

Michelle died peacefully in her special room, surrounded by all her artifacts. Ron was not able to be present for fear of being implicated.

This exit left all of us with much sadness and yet a certain satisfaction, knowing that Michelle did not have to suffer anymore, and Ron did not have to worry about his health getting in the way of caring for her.

SADD awaits 1st test case

The plight of this couple, with their growing Alzheimer's nightmare, was first shared here almost three years ago. Their names were changed to protect their privacy, so they remain "Ron" and "Michelle."

About that time, FEN had launched a nationwide initiative intended to strengthen end-of-life safeguards through a new Supplemental Advance Directive for Dementia Care (SADD). In conjunction with other Advance Directives, it could ensure that people who have signed it when mentally competent will have it honored when they are no longer of sound mind.

SADD's special focus is to ensure that a patient's directive not to be manually fed or hydrated is obeyed by their hospital, hospice, or care facility.

The SADD program is for people who may lose competence but do not want to lose control of their death. When that time comes, FEN will litigate *pro bono* on their behalf if their SADD document is not followed.

Michelle was the first to sign up, and the couple agreed to tell their story. Ron was willing, he said, "if it's something we can do to help promote self-determination in end-of-life matters."

Alzheimer's would not let them wait long enough to be a test case.

FEN now has others who may one day help break legal ground on behalf of suffering people and their dying requests. In addition, SADD enrollment can now be accessed when needed by emailing: info@finalexitnetwork.org

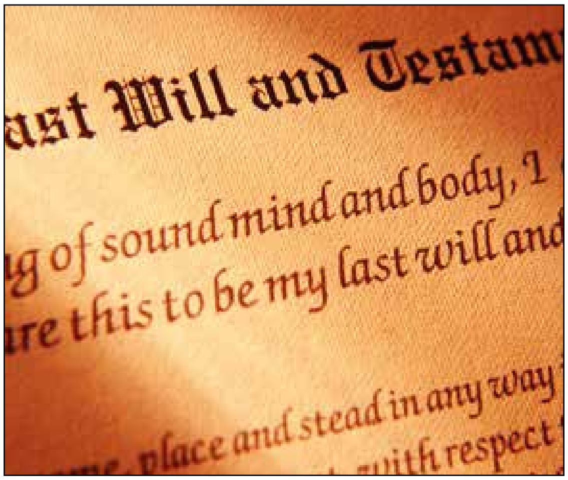
– Jay Niver, Editor

Where there's a will …

The gifts that generous members and friends bequeath to FEN upon death are an important funding source.

Please remember us in your will, or name FEN as a beneficiary in your IRA or other financial product. All you need is our tax ID (80-0119137) and address: Final Exit Network, Post Office Box 10071, Tallahassee, FL 32302.

If you have any questions, we'll be happy to answer them – just phone us toll-free at 866-654-9156, or send us an email at info@finalexitnetwork.org. We'll help you through the easy process to leave a right-to-die legacy and help others.



Discuss your AD with doctor – *Medicare covers it*

DEA could keep drugs from terminal patients

By Janis Landis, FEN Board Member

Do you feel awkward asking your physician to make time to discuss your Advance Directive (AD) and treatment preferences?

Fortunately, the US Medicare system recognizes the importance of these talks, and they are billable – just as any other medical discussion with your doctor.

It's *one step forward* for what some claim is "the world's best healthcare system."

Unfortunately, the Drug Enforcement Agency (DEA) is proposing a *bigger* step backward: requiring terminally ill patients to visit their doctors in person before they can write them prescriptions.

First, the good news.

There are two specific codes for MDs to use in getting reimbursement. So, when making your appointment, let the doctor's office know you want to include time for an EOL conversation. You pay nothing for this planning if your doctor or other healthcare provider accepts assignment, and it's part of your yearly "wellness" visit.

If it's provided as part of your medical treatment, the Part B deductible and co-insurance apply.

Medicare also requires hospitals and skilled nursing facilities to ask at the time of admission whether you have an Advance Directive – and to note its existence in your medical record.

Now, the bad news.

The DEA has proposed a new rule for prescribing controlled drugs. During the COVID crisis, "telehealth" (phone or online communications) became a vital link to healthcare. In recognition of that, the DEA waived the in-person requirement for certain drugs.

Now, with the easing of pandemic restrictions, the DEA is proposing that these drugs must once again be prescribed only in an actual visit to a physician.

In states with legal Medical Aid in Dying (MAiD), there is considerable concern that this will create an obstacle for individuals seeking medical prescriptions for the required "lethal drug cocktail" that can deliver a peaceful, compassionate exit to a terminally ill patient.

Special delivery – DwD representatives deliver nearly 10,000 public comments to the DEA opposing a proposed mandate that patients must see physicians in person to receive a prescription.

Obviously, MAiD applicants are not in good health, and the trip to a prescribing doctor may be very arduous. This is particularly true in rural areas where a participating MD – one who is willing to support a MAiD death – may not be readily available.

To be clear, the DEA rule was not aimed at making MAiD more difficult. The rule is a very well-intended effort to deal with the enormous problems of drug addiction, like opiates. But the impact on MAiD could be an unintended, disastrous side effect for suffering people who desperately want end-of-life choice.

When the DEA announced the idea to restrict telemedicine, Death with Dignity (DwD) mobilized a national campaign to collect public comments opposing it. They gathered nearly 10,000 protesting comments from across the country.

On March 31, the coalition hand delivered them in person directly to DEA headquarters – *which hypocritically said they preferred comments to be submitted online.*

Your next step.

These issues exemplify the way our government may intentionally (or not) help or hinder end-of-life autonomy. This is why FEN does not follow the "medical model" requiring the government and a doctor to support your decision to end your suffering.

We believe that you are the only one who must give permission when intractable illness has made life intolerable.

So, be sure your next step is to renew your FEN membership, donate if you can, and spread the word.

Be with us now, so we can be with you later.

Budget ‘grants’ progress

– New, live workshops scheduled –

From Executive Director Mary Ewert

At its April meeting, our Board of Directors reviewed the FY2023-24 budget, which is designed for a Final Exit Network that is ready to flex its muscles. With our financial systems in place – CRM database conversion concluded, and grant research underway – we’ll focus in this new fiscal year on securing at least $150,000 in grants, expanding our educational components, growing communications across social media platforms, and further developing partnerships with state-based end-of-life organizations.

> ***Participants will learn about the options for comfortably and safely hastening death, and how they can better position themselves for choice in dying.***

All these developments have one overarching goal: to provide benefit to our members.

Supported by a generous grant from the William H. Donner Foundation, planning for “Are You Ready? End of Life Options Workshops” is moving forward. Pilot sessions were scheduled May 6 in Portland, OR, and May 7 in Everett, WA, north of Seattle, as this magazine went to press (registration is closed).

The goal is that participants will learn about the options for comfortably and safely hastening death, and how they can better position themselves for choice in dying, as well as understand the use of inert gas for rational self-deliverance.

In the coming year, we plan to take the workshops on the road to cities where there are concentrations of FEN members, and we will let members know as soon as more meetings are scheduled.

The workshops are for FEN members who are at least 50 years of age and not planning to end their life in the near future. We are looking to making parts of the workshop available through Zoom, and we will keep you abreast of those developments.

Questions about the workshop program can be directed to: workshop@finalexitnetwork.org

The virtual *Chosen Death Forum*s are now firmly established on the first Monday of each month. These Zoom-based discussion groups, initiated by volunteers Deborah Alecson and Jim Van Buskirk, provide a safe space to discuss topics surrounding EOL options.

The program is growing, with four experienced facilitators and three more coming on board soon. This expansion will allow members who apply each month to participate in groups properly sized for effective discussion.

Watch your email for forum registration info sent out prior to each meeting.

Speaking of email – members have begun receiving notices about updating/providing their email addresses. In this era of digital communications, sharing your email address with us is crucial if you want to participate in programs like the *Chosen Death Forum*. Within the next few weeks, emails will be sent to all email addresses we have on record, even if there are two or more under one account.

Be assured, we will not share your online address with other organizations, and we promise not to inundate your inbox. If we do not receive your email address, you will be mailed a letter giving you an opportunity to provide one.

Much work remains. With your continuing support, we move forward!

You asked: *“Why have FEN membership cards been phased out?”*

They are no longer sent with new-member packets because they served no practical purpose. No one asks to see your card and verify membership – it gains you no retail discounts or ID for a traffic stop, nor does it serve as an Advance Directive or DNR instruction.

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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.

CA group seeks to liberalize MAiD law

By Janet Hager, Contributor

A new California group, "A Better Exit," is trying to expand California's End of Life Option Act via a legislative proposal.

They are grateful that California has MAiD (medical aid in dying) available, but feel California's law is very restrictive, particularly when compared to other countries that have legalized MAiD.

While A Better Exit appreciates the work that Compassion & Choices has done to establish MAiD in the 10 states and District of Columbia where it is available, Compassion & Choices' goal is to get the same, 26-year-old law in every state before looking at ways to improve it.

A Better Exit doesn't think Californians should wait for that to happen, and the group is requesting the following three changes to the current statute:

1. Broaden MAiD eligibility criteria to include individuals who are suffering from grievous and irremediable diseases and have life expectancy longer than six months.

2. Allow an individual the choice to self-ingest or receive an IV infusion when utilizing MAiD, in accordance with their personal preferences and medical needs.

3. Allow people with early to mid-stage dementia to be evaluated for and have access to MAiD, when two physicians find that they have sufficient capacity to understand the consequences of their choice.

To support or learn more about this legislative proposal, visit www.ABetterExit.org.

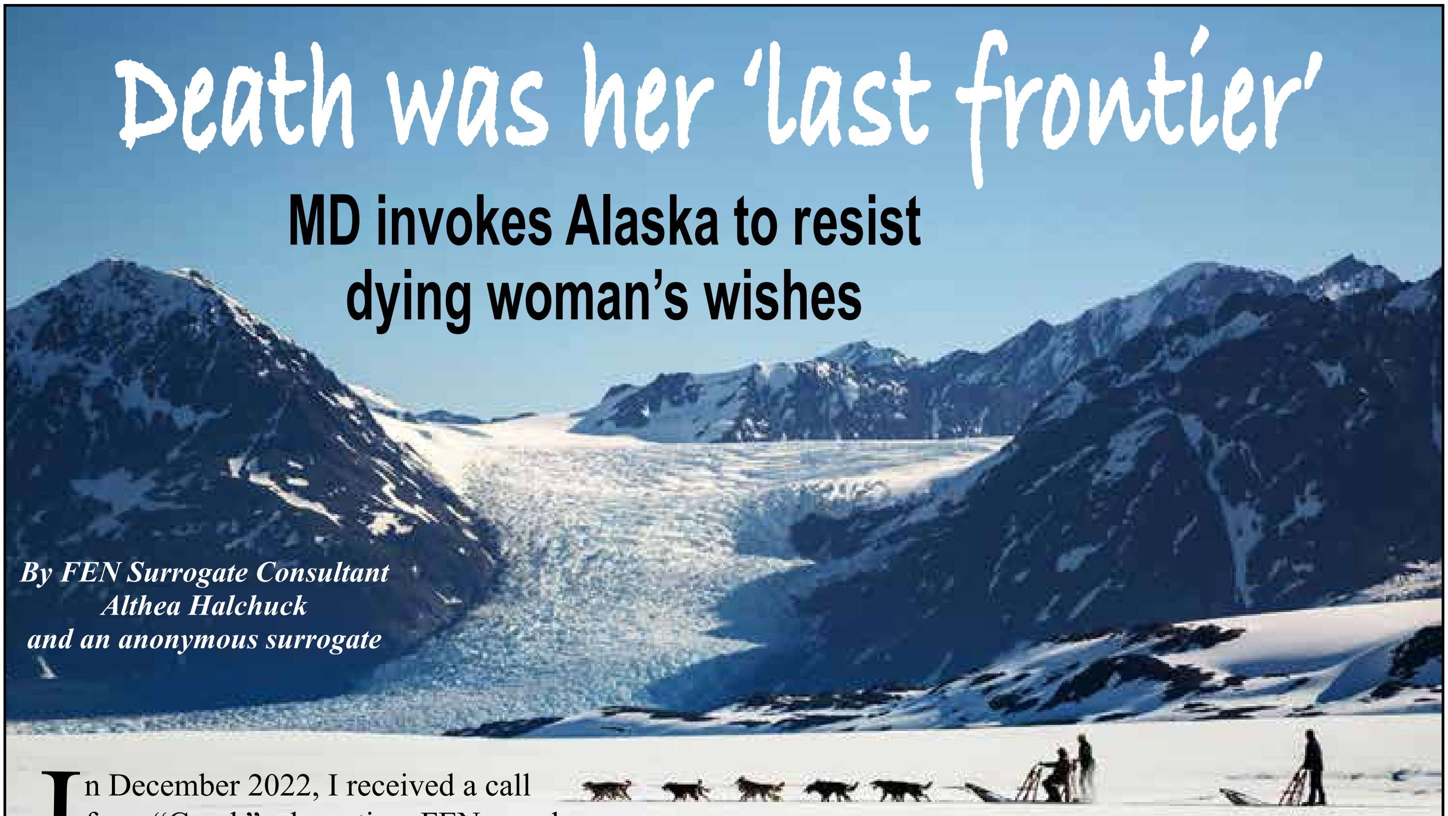
Just as Brittany Maynard became a recognizable advocate for MAiD, *A Better Exit* is looking for individuals who might be willing to share their stories of wanting to receive medical aid in dying but aren't eligible under the current, restrictive California law.

If you or someone you know would be willing to discuss this possibility with A Better Exit, please email us: ABetterExit@gmail.com.

Death was her 'last frontier'

MD invokes Alaska to resist dying woman's wishes

By FEN Surrogate Consultant Althea Halchuck and an anonymous surrogate



In December 2022, I received a call from "Carol," a long-time FEN member, asking for my help with her duties as a health-care Power of Attorney (HC-POA) for "Evelyn." This is her story, in her own words. Names have been changed to protect their privacy.

My best friend of 50 years, Evelyn, is a patient in a large Boston teaching hospital. Doctors are not respecting her, or me as her HC-POA, or following her Advance Directives. I need your help.

She has nearly a dozen severe co-morbidities and has endured continual pain for the last 15 months while recuperating from three surgeries. She is very clear about her end-of-life wishes, which we've discussed many times: no more surgery, no intubation, no artificial feeding, no antibiotics, and no resuscitation.

Several days ago, after a 911 call, Evelyn was transferred to her treating surgeon (TS). I was told she had consented to surgery, requiring intubation. During an eight-hour operation, they discovered a blood clot and suspected part of her bowel might have died. She was in critical condition – the prognosis was hour-by-hour. On Day 2, she was extubated; on Day 3, she was up doing physical therapy, but in lots of pain.

We immediately updated her DNR and POLST (Physician Orders for Life Sustaining Treatment), indicating comfort-focused treatment only – no resuscitation.

She didn't stabilize, the pain increased, and the doctors decided – without asking for consent – to withdraw food and oral meds to help her bowel recover, requiring a feeding tube. Then they installed a PICC line (peripherally inserted central catheter) to give her nutrition or medication.

They claimed Evelyn was on the road to recovery. Conflicted as I was, I didn't want to withdraw treatment, which would mean certain death.

Two weeks later, the attending surgeon (AS) called to say immediate surgery was needed to discover the cause of her pain, suspecting a dead bowel. She claimed if Evelyn didn't have this surgery, she would likely suffer a long, slow death from sepsis. Although she had consented to the surgery, doctors weren't sure she understood, and they wanted my consent. Despite my better judgment, I agreed.

An hour later, her nurse called and said when they came to take her to surgery, she didn't want to go, was kicking and screaming, but they took her anyway. I immediately called the OR to withdraw consent. Realizing I needed FEN's help, I promptly placed a call requesting Althea's help.

Within an hour, on a conference call, both the treating and attending surgeons pleaded with me

The treating surgeon's goal was to get Evelyn well enough for 'one last Alaska dog-sled adventure' – he pushed treatments and surgery on a dying woman rather than refer her to hospice.

to consent to two possible operations.

The TS said this was a "fixable" condition – they could go in and "take a look see." The other surgeon said, "I can't agree." But the treating surgeon refused to take no for an answer and proceeded to discuss procedures and argue. He applied additional pressure, saying he would not give her huge doses of pain meds to let her die or put her in hospice.

Finally, the anesthesiologist (also on the call) said, "I know her. I've participated in her last three surgeries, and she wouldn't want this." With that, I firmly cut off discussion with their promise to transfer Evelyn to comfort care – *with no surgery.*

He had an answer for every question and objection I had about bad outcomes. He was *not* going to transfer her to hospice, period.

Later that evening, the AS called to say, "I think we made the right decision."

I was confused, as she had advocated for surgery until the last minute. The following morning, she called to say the treating surgeon had talked Evelyn into an operation – but the attending physician didn't think she was competent to decide.

I demanded a call from the TS.

While Althea listened in, he again pleaded for surgery. He had an answer for every question and objection I had about bad outcomes. He was *not* going to transfer her to hospice, period.

I told him firmly yet again: Evelyn's wish was for no treatment. He finally agreed to call in Palliative Care (PC).

I spoke with the palliative team, and it was a complete and complex phone call with *no* push-back! They reiterated that I had full control to make the decisions. They were totally supportive to immediately withdraw antibiotics and feeding, confirming what Althea had said about my right to decide things.

Still, after all this, PC had to wrest control from the treating surgeon because he claimed "the team was still debating whether to put Evelyn with hospice."

When I walked into her room the next day, she said, "Thank goodness you're here; I can go now."

Finally, after many weeks, I enrolled her in hospice. I had to advocate every step of the way to ensure she was receiving adequate pain medication.

After six days in hospice, she peacefully passed.

Althea adds context

Carol called me midway through her struggles on behalf of Evelyn. She encountered doctors who refused to listen, had their own agendas, or gave conflicting information. The treating surgeon's goal was to get her well enough for "one last Alaska dog-sled adventure" – he pushed treatments and surgery on a dying woman rather than refer her to hospice. Another issue: Evelyn was in and out of mental capacity, not realizing the consequences of surgery or understanding doctors' requests.

After reviewing Evelyn's EOL documents, I determined Carol was her HC-POA and had every right to make her medical choices. I had suggested Carol reach out to Palliative Care for a consult – *and to contact the Ethics Committee.*

Carol was a strong and intelligent advocate being ignored, and pushed and pulled in every direction. She was also in the midst of anticipatory grief over her failing friend. At various points, Carol was angry, frustrated, confused, and conflicted.

After she spoke to Palliative Care, Carol wrote me: "The biggest compliment I can give is speaking with PC felt *almost* as good as speaking with you – you have helped me immensely. I thought I was a knowledgeable advocate, but I never imagined there would be so many roadblocks. As the journey unfolded, a nurse and two doctors remarked, 'When it's my time, I hope I have an advocate like you.'

"Knowing you were there helped infuse me with strength. I am so very grateful ..."

[Final note: Most literature suggests that without antibiotics, sepsis is often a quick and painless death, in as little as 12 hours, unlike what the surgeon said.]

Share your personal story

If you've had an unfortunate EOL healthcare experience – with the medical system, hospice, care facilities, or Advance Directives – please feel free to let us know (we can keep you anonymous).

Contact Final Exit Network at 866-654-9156 or info@finalexitnetwork.org

Q: What is 'a good death'?
A: Let the patient decide

By Marilyn Mendoza, MD, FEN Blog Contributor

We rarely give much thought to our own death until it is upon us. Sigmund Freud said we are incapable of imagining it. Even though we know and can imagine someone else's demise, we are convinced of our own immortality. As a result, we give little or no thought to how we would like our last days and moments to be. Or, for that matter, even what we need to do to ensure that our wishes will be carried out.

People often talk about a "good" or a "bad" death. For the patient and family, what constitutes those ideas may be different. If you ask 50 people what they consider to be a good death, you might easily get 50 different responses. Most people would feel that a peaceful, painless death would be considered good. A bad death would be one involving violence, severe pain, torture, dying alone, being kept alive against your wishes, loss of dignity, and being unable to let your wishes be known.

No one wants someone to suffer as death is near. These are some of the "bad" deaths that can be traumatizing for the dying, their family, and medical staff. What one chooses as a good death is subjective and should be based on the patient's wants and needs. For example, the loved one may want to die quickly while asleep. Still, this might be traumatizing for the family.

California researchers who reviewed studies that examined what constituted a good death, or dying well, found 11 areas associated with that goal. The three main areas were: giving specific information about how they wanted to die; being pain free; and being emotionally well by addressing the quality of the life they want in their time before death.

Other factors were religion or spirituality, and having a sense of completion of their lives. Dying people want to have choices in their treatments, to be treated with dignity, have a good relationship with medical providers, and be with family to say goodbye. Additionally, I would add another factor based on hospice nurses' reports. They comment that when the dying experience a deathbed vision of a departed loved one, it helps to calm and soothe them for a more peaceful death.

Some would say that calling a death "good" is a value judgment that might not be the patient's. Therefore, a newer model for EOL care has been developed, called a Respectful Death, in which the dying, the family, and professionals all work together and support each other to achieve the best possible outcome for the patient. One would assume they were already doing this – sadly, that's not always the case.

Decisions are made unilaterally without considering what the patient wants or needs. A respectful death involves truly listening and being open with them and family about the diagnosis and future. The patient, family, and medical team often engage in a conspiracy of silence where no one even acknowledges that someone is dying.

If there was one word to describe the secret of a good or respectful death, it would be "communication." We need not be near life's end to begin discussing what our wishes are. Do we want to die at home? Does the place matter, so long as family is there? Do we want to be kept alive at all costs – do we not want to be resuscitated? Knowing these and similar matters helps everyone.

There are many accounts of families unaware of what their loved one wanted and having to make agonizing decisions about their care. However, once there is open communication and an understanding of the values and goals of the dying and family, a respectful death can be achieved.

[The preceding article was first published in Psychology Today, *then it was posted on* The Good Death Society Blog.

The author is in private practice in New Orleans, focusing on grief, bereavement, trauma, and women's issues. She is a clinical instructor in the Department of Psychiatry and Neurology at Tulane Medical Center, has appeared in the media, published numerous articles, and wrote We Do Not Die Alone: Jesus Is Coming to Get Me in a White Pickup Truck.*]*

Dr. Marilyn Mendoza

Do Not Ask Me to Remember

(From Alzheimer's – Poems for Pathfinders)

Do not ask me to remember,
Don't try to make me understand,
Let me rest and know you're with me,
Kiss my cheek and hold my hand.

I'm confused beyond your concept,
I am sad and sick and lost.
All I know is that I need you
To be with me at all cost.

Do not lose your patience with me,
Do not scold or curse or cry.
I can't help the way I'm acting,
Can't be different alhough I try.

Just remember that I need you,
That the best of me is gone.
Please don't fail to stand beside me,
Love me 'til my life is done.

– Owen Darnell

Look to the past for future guidance

Don't be plagued by preparing to die

By Lydia Dugdale, MD, FEN Blog Contributor

The Centers for Disease Control continues to report that COVID-19 remains much more likely to kill people over 65. That's the bad news.

The good news is that there exists a time-tested model to prepare for death. And, if COVID-19 statistics do anything for us, they should cause all of us to stop and consider whether we are prepared to die.

In the 1350s, the Black Death (Bubonic Plague) ravaged Western Europe. Historians estimate that it killed up to two-thirds of the population. Priests themselves were not immune, and the laity was often forced to face death without last rites or proper burials. Consequently, people feared for their souls.

With the possibility of disease, famine, and war never far from the collective imagination, Black Death survivors asked for help. They insisted on knowing how to ready themselves for death's inevitable arrival.

By the early 1400s, handbooks on preparing to die began to circulate. They were known as the *ars moriendi,* Latin for "art of dying." The author of the original text is unknown, but was likely an affiliate of the Catholic Church, then Western Europe's leading social authority. But the *ars moriendi* developed many spin-offs, including an illustrated version for the illiterate and instruction for the non-religious.

This art of dying fell out of favor about a century ago when the Roaring '20s promised new life and luxury.

Widely popular for more than 500 years, these various iterations meant that no one should meet death unprepared.

This art of dying fell out of favor about a century ago when the Roaring '20s promised new life and luxury. The discovery of penicillin in 1928 suggested that death might be thwarted indefinitely, and societal norms began to shift – emphasis on the art of dying well quickly ceded ground to the art of living well.

As cardiopulmonary resuscitation (CPR), life support, and organ transplantation proliferated, death was pushed even further from view.

It's no wonder that the thought of death gives us anxiety. Few of us, if any, have given much thought to it, beyond life insurance and estate planning. (This is true even for many of my physician colleagues.)

But it's not too late. And several lessons from the *ars moriendi* literary genre merit consideration.

First, dying well requires living well, and living well means that a person must live with the end in sight. Acknowledging human finitude does not mean dwelling on morbid thoughts, but it does mean inviting the possibility of death into daily existence.

> ***Americans are more comfortable talking to their children about 'safe sex' and drugs ... than to their elderly parents about end-of-life wishes.***

When my own middle-school children asked about COVID-19, I spoke openly with them about the death rates and about how good health is not guaranteed.

It's astounding that Americans are more comfortable talking to their children about "safe sex" and drugs (important as this is) than to their elderly parents about end-of-life wishes. We must reclaim a recognition of our mortality.

Dying well also requires community. No version of the *ars moriendi* expected that a person can die well in isolation: Dying was always a community affair. The art of dying was sometimes described as a great drama in which the dying person played the starring role and community members were supporting actors.

Everyone, including children, had a role to play. When a friend of mine with young children died, many in our peer group wondered whether the funeral was appropriate for our children. I took mine, and it made sense to them. By participating in the funeral, they witnessed how a community can serve to bear the sorrows of its members, and they began to understand themselves as finite beings.

'Encouragement in Faith,' c. 1450

The *ars moriendi* developed in the late Middle Ages, an era arguably more enchanted than our own. It's thus easy to see why many of its versions gave attention to metaphysical and religious questions.

Even though religion is on the decline in the United States, it would be a mistake to assume that we have progressed past existential wonder. About 70 percent of Americans still identify with some religious faith. What's more, many of my patients ask religious questions as death approaches. Somehow death brings, "What happens when I die?" to the fore. These are the types of questions the *ars moriendi* encouraged its readers to consider.

Critics will doubtless assert that progress lies in looking to the future. But when sickness and death strike, sometimes guidance from the past offers the clearest path forward.

[A version of this essay was first published in Psychology Today. *The author is an associate professor of medicine at Columbia University Vagelos College of Physicians and Surgeons, and Director of its Center for Clinical Medical Ethics. She focuses on end-of-life issues, medical ethics, and doctor-patient relationships. She edited* Dying in the Twenty-First Century *and wrote* The Lost Art of Dying: Reviving Forgotten Wisdom.*]*

FEN YouTube channel now online

In February, Final Exit Network's Outreach & Education Committee approved the launch of FEN's official YouTube channel.

The aim is to collect and consolidate videos that best present correct information to viewers seeking to learn about us.

The eight-member YouTube project team scanned the Internet for FEN-related videos that have been circulating for years. Most of them are outdated, incorrect, misleading, or inappropriate. Of those, we more closely reviewed more than 30 videos we felt may have potential to make a truthful online presentation for FEN.

Our official YouTube channel now includes an initial playlist of five videos. We have identified footage of personal end-of-life stories suitable for three more.

A professional videographer will be contracted to develop more videos on FEN's values, mission and services. Our goal is to have a playlist of 10-12 high-quality pieces that will provide correct, up-to-date information about Final Exit Network, told through us or the experiences of others who are willing to share.

Check out our channel. Please share it with your friends and family, *and don't forget to subscribe!*

‘Good Death’ blog gains life daily

By Jay Niver, FEN Editor

It was almost within hours of April 1 when *The Good Death Society Blog* recorded its 100,000th visit. But it was no April Fool’s joke when co-editors Gary Wederspahn and Melanie Raine proudly announced that FEN had reached lofty milestone.

August will mark six years since the blog’s humble beginning, started by Gary and Lamar Hankins in 2017. Now it has collected nearly 300 insightful posts of varied lengths discussing scores of topics.

On average, more than 60 readers per day visit the site to learn about everything from “green burials” and psilocybin to VSED, wills, and disability rights.

“This archive is an excellent resource for people who are facing a variety of end-of-life issues and challenges,” said Gary. “We encourage FEN members to download and share posts with friends, associates, and family who may enjoy or benefit from them.”

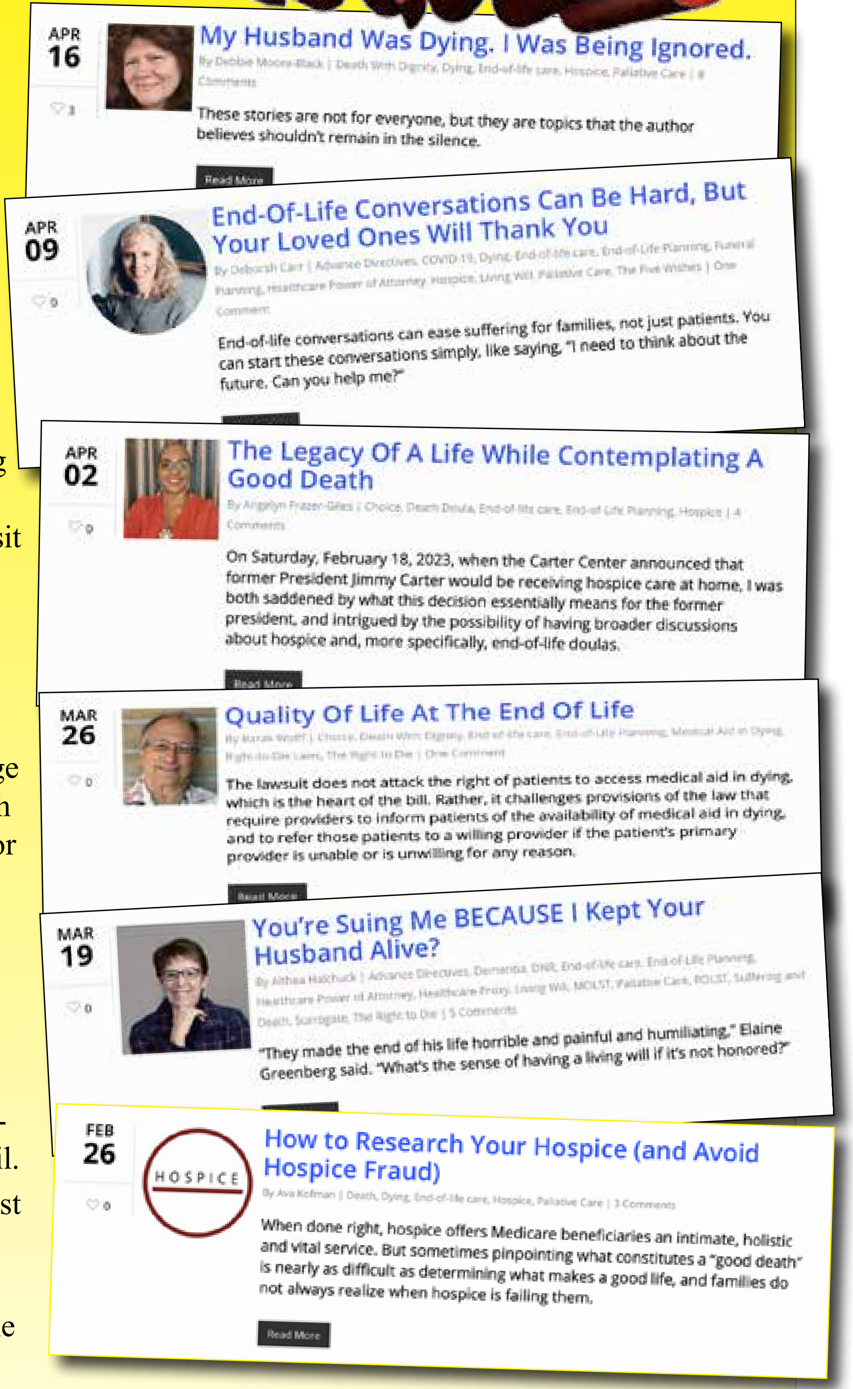
There are three ways to access *The Good Death Society*’s wealth of material.

1. Use the search function to select a topic or click on a category from the drop-down menu at bottom right. When you’ve found an article to share, easily forward it by highlighting and copying the link and pasting it into the text of an email.

2. You can also copy and paste the blog post into a word document you can print, copy, and share.

3. Or you can use the “Share” buttons at the end of each post.

These readings may be valuable, timely conversation starters or discussion topics. If these prove useful, you can recommend to others that they become subscribers and receive each post in their email by simply entering their email address in the space on the right side of the page, then clicking on “Sign Up.”



My Husband Was Dying. I Was Being Ignored.

By Debbie Moore-Black | Death With Dignity, Dying, End-of-life care, Hospice, Palliative Care | 8 Comments

These stories are not for everyone, but they are topics that the author believes shouldn’t remain in the silence.

End-Of-Life Conversations Can Be Hard, But Your Loved Ones Will Thank You

By Deborah Carr | Advance Directives, COVID-19, Dying, End-of-life care, End-of-Life Planning, Funeral Planning, Healthcare Power of Attorney, Hospice, Living Will, Palliative Care, The Five Wishes | One Comment

End-of-life conversations can ease suffering for families, not just patients. You can start these conversations simply, like saying, “I need to think about the future. Can you help me?”

The Legacy Of A Life While Contemplating A Good Death

By Angelyn Frazer-Giles | Choice, Death Doula, End-of-life care, End-of-Life Planning, Hospice | 4 Comments

On Saturday, February 18, 2023, when the Carter Center announced that former President Jimmy Carter would be receiving hospice care at home, I was both saddened by what this decision essentially means for the former president, and intrigued by the possibility of having broader discussions about hospice and, more specifically, end-of-life doulas.

Quality Of Life At The End Of Life

By Barak Wolff | Choice, Death With Dignity, End-of-life care, End-of-Life Planning, Medical Aid in Dying, Right-to-Die Laws, The Right to Die | One Comment

The lawsuit does not attack the right of patients to access medical aid in dying, which is the heart of the bill. Rather, it challenges provisions of the law that require providers to inform patients of the availability of medical aid in dying, and to refer those patients to a willing provider if the patient’s primary provider is unable or is unwilling for any reason.

You’re Suing Me BECAUSE I Kept Your Husband Alive?

By Althea Halchuck | Advance Directives, Dementia, DNR, End-of-life care, End-of-Life Planning, Healthcare Power of Attorney, Healthcare Proxy, Living Will, MOLST, Palliative Care, POLST, Suffering and Death, Surrogate, The Right to Die | 5 Comments

“They made the end of his life horrible and painful and humiliating,” Elaine Greenberg said. “What’s the sense of having a living will if it’s not honored?”

How to Research Your Hospice (and Avoid Hospice Fraud)

By Ava Kofman | Death, Dying, End-of-life care, Hospice, Palliative Care | 3 Comments

When done right, hospice offers Medicare beneficiaries an intimate, holistic and vital service. But sometimes pinpointing what constitutes a “good death” is nearly as difficult as determining what makes a good life, and families do not always realize when hospice is failing them.

Feel free to contact us if we can help in any way, and thank you for subscribing to *The Good Death Society Blog*! Comments and suggestions are welcome any time – and read two recent blog posts reprinted on pages 8-10 in this issue of our quarterly magazine.

More Good Endings

Book Reviews by Jim Van Buskirk

Blair Bigham, MD

Death Interrupted ... (2022)

“This book is about a place worse than death. A place where doctors despair at the hope families cling to as we poke and prod the patient, pandering to our own egos, afraid to acknowledge that we have failed in our role as life savers.

“It is about the space between alive and dead, a space I hope never to occupy personally, but one I am guilty of filling, over and over again, with others I’m tasked to care for.”

In this, his first book, award-winning journalist, scientist, and physician Blair Bigham adroitly articulates the fear that many of us have.

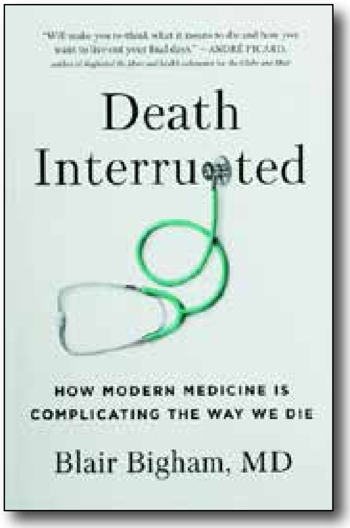
He knows whereof he writes, having trained in emergency and critical-care medicine, been a journalism fellow, co-host of the *Canadian Medical Association Journal* podcast, and deputy editor at healthydebate.ca. His clinical work in Australia, Nepal, South Africa, and elsewhere allowed him to witness the relationship between wealth and health on a daily basis, and he has reported on the under-told stories of patients, healthcare providers, and the systems that help or fail them.

The tagline for his website (blairbigham.com) is “Health journalism that matters.”

This engagingly presented hybrid of personal memoir, investigative journalism, and well-researched history provides a behind-the-scenes glimpse (including in-house lingo) into various arenas of the medical profession. Interweaving his own observations working in ambulances, emergency rooms, and the ICU with conversations with other critical care and end-of-life professionals, Bigham exposes the tensions inherent in this new era of dying by addressing the tough questions.

> ***These two memoirs by physicians at opposite poles of their impressive careers offer personal perspectives on the medical establishment – one in Canada, the other in Britain. Their experiences and insights can be contrasted to how the US medical-industrial complex operates.***

He offers insight into untangling the complicated, controversial relationships between medicine and ethics, and religion and legality, while giving short shrift to the financial and/or insurance incentives (understandably, given he works in Canada). He explores the fallibility of prognostication and admits that his work in the ICU contributed to his tunnel vision.



“When there is a choice to be made, it is not mine alone, but I play an integral role,” he writes. “My honest and clear assessment, and how I communicate it to loved ones, can ease the decision to let go of someone in a controlled, peaceful way.”

The doctor continues: “But too often there is ambiguity, and it leads to decisions being deferred – the direct consequence of which is more suffering.

“The death dilemma is, to some extent, a result of our often indiscriminate application of technology to prevent in the short term a death that will ultimately come anyway, but it also stems from our failure to address the ways our dependence on technology has dehumanized the practice of medicine and the process of dying.”

He later writes, “Doctors tend to think of death as falling into one of two categories: somatic death, which occurs when the heart has stopped and can’t be restarted; and neurologic death, or brain death, which occurs when there is an irreversible loss of consciousness and brainstem function, including the ability to breathe.”

Finally, Dr. Bigham summarizes the death dilemma equation:

Technology x (Resuscitation Glorification + Death Denialism) = False Hope by suggesting that to solve the equation, one must move technology out of its central role. “When ICU doctors love their patients and understand their families, and when families understand the limitations of medicine at the end of life, we can form an alliance to honour a person's life with a loving end."

He ends succinctly with four steps:

- Think about death;
- Talk about death (with friends and family);
- Write about death (legally document your wishes); and
- Live your life ("it's easier to live your life when you've already planned for your death").

Henry Marsh

And Finally ... (2023)

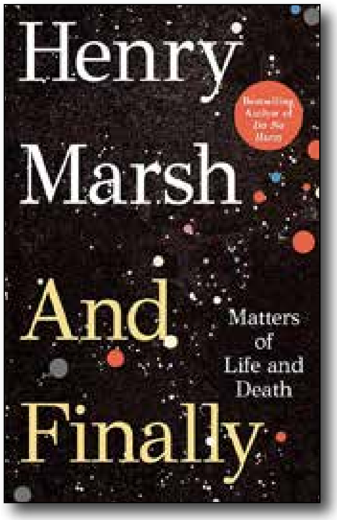
Henry Marsh's *And Finally: Matters of Life and Death*, follows his 2014 memoir, *Do No Harm: Stories of Life, Death and Brain Surgery,* and 2017's *Admissions: A life in brain surgery.* The bestselling author and neurosurgeon offers an unflinching and deeply personal exploration of death, life and neuroscience.

"I worked as a neurosurgeon for over 40 years. I lived in a world filled with fear and suffering, death and cancer," he writes. "Like all the doctors, I had to find a balance between compassion and detachment. This was sometimes very difficult, but rarely if ever did I think about what it would be like when what I witnessed at work every day happened to me.

'*Rarely if ever did I think about what it would be like when what I witnessed at work every day happened to me. This book is the story of how I became a patient.*'

"This book is the story of how I became a patient."

Though unprepared for the impact of his diagnosis of advanced prostate cancer, the retired brain surgeon based in London pulls no punches: "Much of what goes on in hospitals – the regimentation, the uniforms, the notices everywhere – is about emphasizing the gap between staff and patients and helping the staff overcome their natural empathy. It is not about helping patients ...



"You realize quickly that these lists [of drug side effects] are not really there to help patients, but to protect doctors and pharmaceutical companies from complaints and litigation."

His observations about the COVID-19 lockdown and his visits to Ukraine are laced with other, seemingly rambling, less-relevant ruminations on various aspects of his life and career, including past failures, yet-to-be-completed projects, and the frustrating inconveniences of illness and old age. He becomes ever more entranced by the mysteries of science and the brain, the beauty of the natural world, and his love for his family: his mother, his wife, his children, and grandchildren.

Of particular interest is chapter 16, wherein Marsh shares his thoughts about aid in dying, including his own. He firmly rebuts the arguments used to defeat a 2015 bill for assisted dying in the House of Commons, highlighting the illogic "that it is illegal to help somebody do something that is not illegal."

The end of the chapter is strongly worded: "To help somebody to a peaceful and dignified death that they have chosen for themselves is an act of care and love ... [opponents] claim to be compassionate, but in reality are responsible for much suffering."

Exploring what happens when someone who has spent a lifetime on the frontline of life and death finds himself contemplating what might be his own death sentence, he does not shy away from his own fears or ambivalence: "I do not want to die – but then, who does? But nor, to state the obvious, do I want to become old and decrepit."

Elegiac, candid, and poignant, this is ultimately not so much a book about death, but about life and what matters in the end.

Together these two powerful and important books by Bigham and Marsh add to a deeper understanding of the individual physicians' responsibility to their patients, to their profession, and to themselves.

(Reviews continue on the following page)

New MAiD publication coming soon

The inaugural *Journal of Aid-in-Dying Medicine* was announced in February at the closing of the 2023 National Clinicians Conference on Medical Aid in Dying.

The first edition is expected to be published this summer or fall by the American Clinicians Academy on Medical Aid in Dying (ACAMAID).

Lonny Shavelson

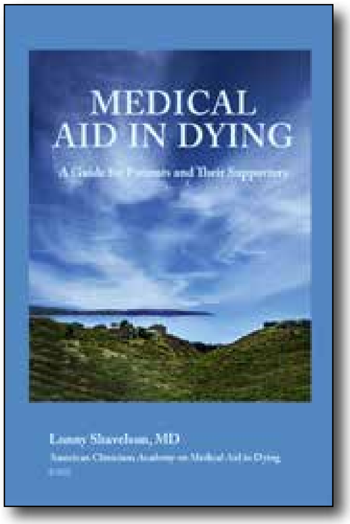
Medical Aid in Dying ... (2023)

Medical Aid In Dying: A Guide For Patients And Their Supporters, published by the American Clinicians Academy on Medical Aid in Dying, is an 84-page publication released in January. It is full of compassionate and supportive care and information on MAiD, in states where it is available.

"This booklet ... originated from the questions, interests, and needs of dying patients, their families, their loved ones, and the many others who support them. Its goal is to de-mystify and facilitate the process of medical aid in dying."

In 2016, when California's End of Life Option Act legalized MAiD, Dr. Shavelson founded Bay Area End of Life Options, a practice dedicated to terminally ill patients. In August 2020, he closed his medical practice and became chair of the newly founded American Clinicians Academy on Medical Aid in Dying (www.ACAMAID.org), focusing on innovating and advancing clinical knowledge and best practices, teaching, and consulting.

"The right for a terminally ill patient to decide how and when to die is both wonderful and complex, filled with awe and anguish. If you are imminently dying, deciding on how you will die is among the most important decisions you'll ever make."



Shavelson's straightforward prose exemplifies the admirable care and respect with which he explains the many elements of MAiD. His detailed, explicit clarifications dispel fears and mistakes that asise from misinformation.

This booklet explores end-of-life terminology; how to have conversations with family and healthcare providers; legal requirements; the roles of palliative care and hospice; and how to find two necessary aid-in-dying MDs (both the attending/prescribing and consulting/second-opinion physicians).

Shavelson describes the five components of the lethal drug mixture, how they are self-administered, and options around the required ability to swallow. He carefully lays out the necessary preparation and planning, leading up to the day itself, and even how using MAiD might affect the grieving process.

This extremely valuable resource, for those who might be considering MAiD, is available through Amazon as a Kindle or paperback or as a free PDF (to read online or download, but not formatted for home printing).

New poll shows vast MAiD support by disabled people

Death with Dignity (DwD) reports that a recent national poll released by a new disability-rights group, "Us for Autonomy," reveals that a clear majority of Americans with disabilities believes Medical Aid in Dying should be legal.

For years, MAiD opponents have said disabled persons don't support it, claiming they could be coerced into using this end-of-life option. Naysayers cite the time-worn (and never substantiated) claim that a "slippery slope" will sweep people in wheelchairs, with debilitating diseases, senility, or merely old age to premature deaths.

The Us for Autonomy survey found that 79% of respondents who live with a disability believe that "Medical Aid in Dying should be legal for terminally ill, mentally capable adults who choose to self-ingest medication to die peacefully."

Additionally, 73% of respondents who live with someone who has a disability are also in favor of MAID being legal.

Notably, political affiliation had little impact on the results, with 79% of Democrats, 65% of Republicans, and 83% of independents in support of legalized MAiD.

The false oppositional narrative continues to surface in every state where RTD legislation is considered, despite numerous safeguards included in every law to protect patients from abuse or coercion.

With more than 60 years' combined MAiD experience in US jurisdictions, there is no verified case of it being used against a person with disabilities.

More than anything, what the poll reminds RTD supporters and activists is that the public supports it. "Opponents' attempts to suggest otherwise are brazen misrepresentations," says DwD.

THE BACK PAGE

A COMPENDIUM OF RIGHT-TO-DIE WORLD NEWS

United States

Nevada – In April, the state's Death with Dignity bill passed through the Health and Human Services Committee for the first time since 2019. The next step is a vote before the full Senate after public comments are submitted.

State lawmakers have called it many things over the years – right to die, death with dignity, medical aid in dying – but prior attempts to legalize physician-assisted death all ended in defeat.

Florida – The woman accused of fatally shooting her terminally ill husband at a hospital was released in March on a $150,000 bond.

Ellen Gilland's freedom comes after the 76-year-old was indicted on lesser charges of assisting self-murder/manslaughter and aggravated assault of a law enforcement officer.

She was originally charged with first-degree murder for firing a single, fatal shot to the head of her 77-year-old husband, Jerry Gilland, on Jan. 21 in what Daytona Beach police called a murder-suicide pact.

Vermont – Terminally ill Connecticut resident Lynda Bluestein, a cancer patient living in Bridgeport, will be able to access EOL care in nearby Vermont, which decided in March not to enforce its residence requirement for MAiD.

Compassion & Choices sued Oregon in 2021 over its residency requirement, arguing that it unfairly discriminated against people from other states. Oregon settled last year, agreeing not to enforce its locals-only provision, and in April, Vermont lawmakers voted to eliminate their live-in rule – now awaiting only the signature of Gov. Phil Scott.

Bluestein will be able to use MAiD if she follows all the law's requirements, including receiving care in the state and, if needed, taking her fatal dose there.

New Yorkers are also eyeing MAiD in Vermont.

France

French President Emmanuel Macron has pledged to draft a law "by the end of summer" in regard to its citizens' right to die.

A "citizens' assembly" has called for legislation to be changed. It included 184 randomly appointed French citizens, compiled according to factors like age, gender, education, place of residence, and occupation to accurately reflect the French population. The youngest participant was 20 and the oldest 87.

The group started debating the issue in December, with its conclusions handed to Macron the first weekend in April. According to the report, 76% said they favored allowing patients the right to some form of assistance in death.

Macron said that any changes made would have to "guarantee the expression of free and enlightened desire" to die, and that medically assisted deaths could only be permitted when the patient in question suffers from an incurable "psychological and physical" condition.

He did not say if euthanasia or aid in dying would be permitted, or if the bill would include both.

The Netherlands

The Dutch government will expand its euthanasia laws to include children ages 1 to 12, saying it will end the "hopeless and unbearable suffering" of five to 10 youngsters each year.

Since the introduction of euthanasia laws in 2002, children as young as 12 have been permitted to be euthanized. However, if they are between 12 and 16, their parents' consent must be sought. If a child is between 16 and 18, the parents must be involved in the decision.

Data show that 7,666 people were euthanized in 2021 – 4.5% of total Dutch deaths.

Australia

The architect of the world's first RTD law, former Northern Territory chief minister Marshall Perron, is urging the Australian Capital Territory (ACT) to allow under-18s and non-terminal patients access to voluntary assisted dying (VAD) when it becomes the seventh Australian jurisdiction to embrace it.

Perron hopes the ACT's appetite for social change will unleash the next wave of VAD reform even though the rollout through the states is not complete.

A discussion paper released in February explores a possibility "mature minors" could end their lives if they met the eligibility requirements for VAD of being near death from incurable illness or medical condition, and enduring intolerable and non-relievable suffering.

The minimum age is 18 in the five states where assisted dying is now in force.

FINAL EXIT NETWORK
PO BOX 10071
TALLAHASSEE, FL 32302

Chambers wears many FEN hats

Grandma belonged to Hemlock

By Jay Niver, FEN Editor

Lily Chambers has a career and resume so varied that you would not be surprised if she fixed your laptop, repaired your car, and grilled succulent BBQ while coaching her clients in myriad, vital ways.

She joined FEN a few years ago after learning of us via “a dear family friend” who was involved in a planned death. FEN’s mission and work captivated her, but Lily had long before been drawn to end-of-life issues through Grandma Carol.

“My grandmother belonged to the Hemlock Society, and she was very ‘death positive.’” Lily said. The friend involved in the exit had also been Carol’s caretaker.

Lily didn’t intend to embrace death with dignity and the right to die, but after learning of FEN and the Exit Guide Program, she went through Guide training.

“It felt like a ‘big click’ for me,” she explained, “that the people who are coming to FEN really need help. To fill that role is one of the most interesting and valuable things anyone could do.”

Helping others is what Lily does in her work as a personal coach, specializing in areas like grief, “energy healing,” and working with artists.

In another era, a “coach” taught kids how to dribble, pass, or hit a golf ball, but *coaching* has become a full-time field for specially trained advisors who help people through all kinds of life challenges.

Lily Chambers

Lily’s varied expertise transfers easily to FEN. Besides being an end-of-life doula and former hospice volunteer, her interpersonal skills have let her mesh easily with FEN staff, volunteers, and other contractors on a number of levels.

After knowing of her interest in the Exit Guide Program, FEN Executive Director Mary Ewert asked Lily if she would contribute in other ways. Her response was an enthusiastic “Yes.”

She started gently with some data entry, then assumed the job of producing FEN’s online *Right To Die News*, the periodic collection of worldwide RTD news emailed to subscribers. Sifting through EOL stories from around the globe “opened my eyes to so many related issues,” she explained.

Now she’s also organizing and providing technical support for the *Chosen Death Forum,* the monthly online Zoom, and working with Janis Landis on curriculum for EOL doulas as FEN partners with them to improve training in their field.

When not coaching clients or helping FEN, Lily has long been involved in providing space for a variety of community arts pursuits, and she’s also a performing artist.