

IN THIS ISSUE

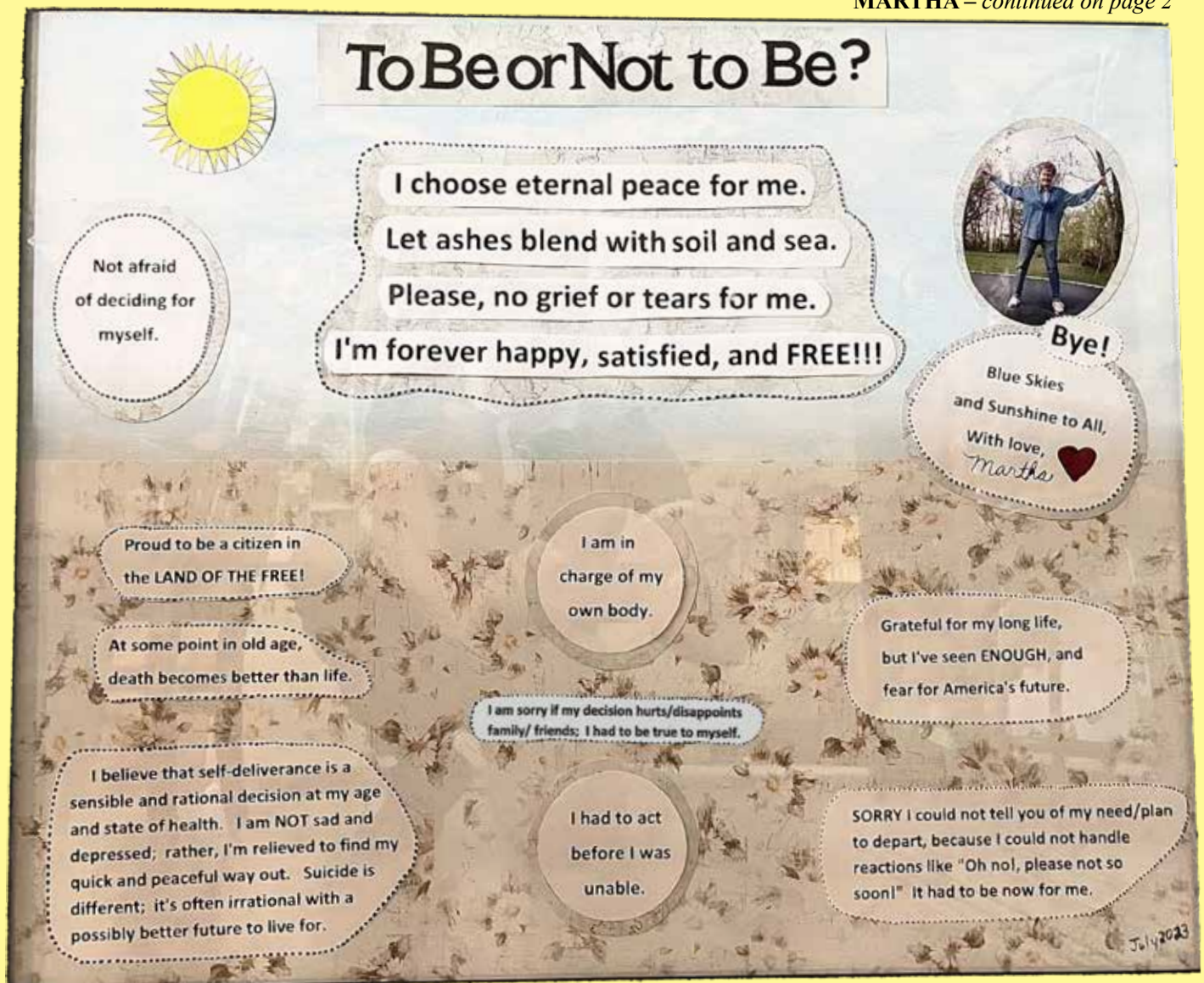
- New board member brings expertise Page 3
- Lifetime member gives same gift to others 5
- Patients have legal right to their doctors' notes 6
- Brother & sister make FEN a family cause 7
- At time to choose, is it quality or quantity of time? 8
- British film star left impassioned RTD statement 14

Martha's resolute way

Dear Family and Friends,

Passing away peacefully in my home is my last primary wish after living 79 Years, with almost all my strength and vigor used up. I choose to meet death willfully and gladly, fully thankful and satisfied with my lifespan on earth. Rather than suicide, I describe my carefully considered choice

MARTHA – continued on page 2



When Martha Fuller took her exit last September 1, this personal poster was with her.

as "planned self-deliverance."

My unconforming way definitely goes back to my parents. When I was 23, my mother died at age 62 after many years of ill health and long, painful suffering. I heard her say a number of times, "I wish I could die!"



Martha Fuller

She also told me she wished she could die in her sleep, like her father, because "that's the best way." It was excruciating for me to witness my mother's agonizing death, while not being allowed to call for help.

Four years later, in stark contrast, my father suddenly died instantly as a passenger in an auto accident. He was 65 and had enjoyed basic good health all his life.

What a huge difference in the funerals and the grieving process for me and my siblings, who had flown in from afar! Mom's funeral was traumatizing, while Dad's was a "celebration of life" with focus on his happy times and special memories.

Ever since I lost my parents, I wanted a quick death like Dad.

As I approach non-existence with gratitude and great relief from fear of suffering, my final vision will be of connecting with my parents and the chain of ancestors who lived and died before me – I am just the newest link in the chain. In my imagination I

“ Ever since I lost my parents, I wanted a quick death like Dad. ”

will picture happily embracing my parents as in a childhood scene. As we're hugging, I will tell them from my heart: "Danke Mutti and Vati! Thank you for your great effort and sacrifice of bringing us to America! Everything turned out fine, and we 3 children all lived much longer than you could have dreamed! AND you have 7 grandchildren, 11 great-grandchildren, and 3 great-great-grandchildren!"

What a joyous reunion it will be!
Love, Peace and Happiness to All!

Martha

ADDENDUM:

9-1-23

When I told my sister of my plans she was aghast and often said: "But you LOOK healthy!" and "You don't seem that much different than 10 years ago!" However, after confiding to her about the reality of my physical deterioration and my years of struggle to "appear" as normal as possible, she now understands and is supportive of my RIGHT to decide.

In my younger years on the farm I could easily lift heavy things like hedge posts, even railroad ties for the ongoing necessary fencing projects. I wrestled cows and calves in springtime calving season, chainsawed untold loads of wood to toss in the basement for our old-fashioned furnace in winter. Physical labor like hay baling in summer, feeding square bales in winter, shoveling snow, corn, & manure, yard and barn work, unloading numerous pickup loads of rock, etc etc. all took a toll on my body over the years. For me it feels like I'm down to 10% of my former bodily strength. There is, of course, no cure for the many serious ailments of a worn out and used up body; in addition, the numerous pain pills I've relied on for over 20 years also have caused significant detrimental side effects.

All my adult life I have been used to solving my own problems, and I know I would be miserable and depressed in a life without complete independence and autonomy. Therefore, I am happy to NOW give up a small amount of longevity in exchange for the double guarantee of attaining my wish for a peaceful, quick exit, PLUS avoiding a possible future in a group care facility. I feel in my heart that another winter could bring on a sudden collapse of one of my seriously ailing systems, resulting in my inability to carry out my relatively easy and quick self-deliverance.

Martha Fuller
9-1-23



BOARD OF DIRECTORS

Brian Ruder, President
Anita Winsor, Treasurer
Randee Laikind, Vice President
Michael Klingler
Janis Landis
Jay Schamberg, MD
Gary Wederspahn

EXECUTIVE DIRECTOR

Mary Ewert

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.

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

 Join us [on Facebook!](#)

  Posting to FEN's Twitter (now X) account @**FINALEXITNETWRK**

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

Klingler brings law, finance skills to board

By Jay Niver, FEN Editor

A Vietnam veteran with a career in business, law, and finance, Michael Klingler joined the FEN Board of Directors in October.

His resume includes a number of impressive professional positions, including seven years as a legal mediator and arbitrator. At one point, he says, seeking “a break from the corporate world, I put on a backpack and traveled around the world for eight months.”



Michael Klingler

He retired as an estate planning attorney in 2010.

Michael, 80, was raised in St. Louis, earning his bachelor’s degree from the University of Missouri and a J.D. from Hastings College of Law in San

Francisco.

Michael says he and his wife, Carolyn, “are committed to helping each other have a ‘good death,’” and both are long-time members of FEN and, before that, the Hemlock Society.

They’re familiar with deaths that were not “good.” “We’ve witnessed the protracted death of my mother in skilled nursing,” he says, “and attended Carolyn’s mom and my former wife through years of Alzheimer’s, and then dying in hospice.”

Michael also saw his brother die from COVID “after two weeks in the ICU because his wife ignored my pleas to let him go.”

He says these experiences have given him “a better understanding and acceptance of death – and a stronger commitment to help end unnecessary suffering at life’s end.”

Michael and Carolyn moved to Arroyo Grande, CA, about nine years ago.



New year – new outreach

– 2024 will mark FEN’s 20th anniversary –

FROM EXECUTIVE DIRECTOR MARY EWERT



Looking back over 2023, FEN continued to be so fortunate to have members willing to give generously of their time to further the aid-in-dying cause.

At its October meeting, the board of directors welcomed a new member, Michael Klingler. A long-time California resident, Michael comes to us with many years’ experience in the legal profession and real estate. He and his wife have been members of the Hemlock Society, and then FEN, for about 25 years.

Thanks to Michael for taking on this role. We are thrilled to have him on board. (See story on page 3.)

□ Our outreach efforts to right-to-die organizations in several states are bearing fruit. In the last issue of this magazine, we featured an article by End of Life Choices California Executive Director Judy Neall Epstein. Brian Ruder and Lowrey Brown are now invited to speak to EOLCCA’s volunteer team in January.

Brian and Lowrey recently spoke to a meeting of the Dignity 50 group, organized by the Death with Dignity National Center for states that have (or hope to have) MAiD laws. These presentations give FEN an opportunity to answer questions that volunteers in other organizations have about what FEN does, and how we fit into the full spectrum of RTD organizations.

□ In 2024, we are planning two special activities to celebrate FEN’s 20th anniversary. First, our prolific book reviewer, Jim Van Buskirk, is compiling an anthology of personal stories that FEN has gathered over past decades. We anticipate the collection will be available in June.

Second, we also hope to release two videos that will be posted on YouTube and available for our speakers and social media efforts. FEN volunteer Russell Bates – a professional film, TV, and commercial director – is very generously donating his time to direct these videos. One will provide an overview of

I thank all of you, our dedicated members, for all you do. I encourage you to continue to scout for stories for this magazine.

FEN, and the other will be an interview of the spouse and family members of a FEN client.

□ I continue working with our fundraising consultant and the FEN board to develop a reliable stream of grant income to enhance FEN’s financial standing, and to support activities such as the videos and other special projects.

We have been extremely fortunate to receive a number of substantial bequests over the past few years, but it’s difficult to budget when revenue sources are unknown. Developing our fundraising capacity with grantors is an important next step.

□ FEN’s member base is solid and will hopefully grow as we work to reach folks who haven’t yet heard about us.

□ Our activities in the FEN “virtual office” take place to support our members, our speakers, our Exit Guide Program volunteers, and everyone who works with us to let our audiences know that there is a peaceful end-of-life option, even when they can’t access Medical Aid in Dying.

• • •

I thank all of you, our dedicated members, for all you do. I encourage you to continue to scout for stories for this magazine. These can be about FEN volunteers or clients, and you – our members – as well.

What brought you to FEN? Why do you support our work? Send story ideas to info@finalexitnetwork.org with “Story Idea” in the subject line.

Let’s look forward to a happy, healthy, and rewarding 2024!



FEN membership makes unique gift

By Jay Niver, FEN Editor

When Valerie Friedman thinks of Christmas presents (or other gifting), she doesn't conjure Amazon, Hallmark, Best Buy, or Macy's. She gives something she already has herself: a lifetime FEN membership.

It's a two-fold gesture that does something meaningful for someone she cares about, and also supports Final Exit Network.

"It occurred to me one day, instead of just sending money to FEN, why don't I bring more people into the fold," Valerie says. "I offer it as a gift to a friend and a benefit to Final Exit. It seems like a win-win to me."

Of course, not everyone would welcome membership in an organization that counsels people about how to die – albeit compassionately and on their own terms, fulfilling end-of-life wishes.

"I just don't offer it to friends willy-nilly," she explains. "Trust me, I know who I'm giving it to."

Valerie is a financial advisor who knows the

importance of advance planning. She no longer takes new clients, but still advises long-time clients who have become good friends over the years. They are generally older, and naturally concerned about EOL issues, and, as Valerie says, "are more interested in the conversation."

Her own involvement in the right-to-die cause goes back to the Hemlock Society, when she sat on its national board and worked with RTD pioneers Derek Humphry, Dr. Richard MacDonald, and Faye Girsh. Hemlock morphed into Compassion & Choices (C&C), and FEN subsequently emerged. Valerie is a lifetime member of both groups.

"I still support C&C, but not with the same passion I have for Final Exit," she says.

Valerie has gifted 10 or 12 lifetime FEN memberships, which cost \$500 each. "It's very important to do what we can to expand FEN's reach," she says. "We have an obligation to support the causes we care about. I can't think of a better way to accomplish this objective."



Valerie Friedman

FEN blog garners praise from new readers

The new year saw *The Good Death Society Blog* reach 160,000 total views (see story on page 13), an impressive way to welcome 2024. New readers who discover it often send comments such as these:

- ... The blog is a rich buffet of food for thought. Thank you so much for sending this along!
- Wow! After browsing the blog and (FEN) Facebook page, I am certainly willing to share with our members ...
- Thank you for the information. I will pass onto our board to approve putting on our website. I also will be signing up for the free service, suggesting to our board members to also sign up.
- Thank you for reaching out and for sharing news on this very important topic that many people find very hard to discuss.
- I just finally got around to checking this out. It's great!

- Thank you for reaching out and for sharing this wonderful resource. I support the idea that everyone deserves the good death of their choosing.
- I have enjoyed being introduced to *The Good Death Society Blog* and have enjoyed reading the posts each week.
- Thank you. I have bookmarked your website ...
- I have visited the site a few times. It's wonderful! Thanks for sharing with me ♥
- Thank you for the information. It's good to know that there are other advocacy sources for this important issue.
- Every time I get contacted by someone regarding Medical Aid in Dying, I start by sending them an email with overview, general info about my practice and resources. I include this blog on the resource list ...

[Google [Death Society Blog](#) to find us on the Net]



Healthcare providers are required to give all their patients electronic access to most kinds of medical files, including access to office-visit notes.

What is my doctor saying about me?

By Janis Landis, FEN Board Member

Fans of *Seinfeld* may remember Elaine's quest to see what her doctors had written about her. Of course, that was played for laughs and – presumably – bore no relation to reality.

So what are your rights? You probably know that you are entitled to all your medical files. Usually, upon request (or automatically in an online portal), you will be given copies of your medical tests, radiologist notes, etc. But what about the notes the doctor is scribbling while talking to you?

Generally, they were not included in your request for medical records. But in a little-noted provision of the federal government's 21st Century Cures Act, healthcare providers are required to give all their patients electronic access to most kinds of medical files, including access to these office-visit notes.

Sometimes referred to as the "Open Notes movement," this reflects the greater transparency now being expected by patients. Most electronic portals (typically run by hospitals or big medical practices) are now automatically including these notes. If yours isn't, you can request a copy.

Why is this important? Usually it won't make any difference. Your physician has undoubtedly provided you either in person, or through available online records, access to all pertinent medical information. But sometimes it is important to know what is being written about your diagnosis and your "cooperation" with the doctor's orders.

This can be really important if you have

something difficult to diagnose, or you feel your pain is not being adequately addressed. Writing "patient complains about severe pain, although no medical cause was found" is different than "as yet, no tests have provided a diagnosis for the patient's severe pain."

Also, medical terminology can be misleading as can comments about the patient themselves. A doctor may state the patient is "not being compliant" with taking medication. This may sound like the patient is being blamed when, in fact, what the doctor meant was that due to other factors (adverse reactions to the medication), the patient stopped taking it.

Perhaps the most important concern is the use of the phrase "patient refused." Your doctor may suggest a referral to physical therapy. Perhaps you don't have a means to get to the PT office. Perhaps you're a primary caregiver for a family member and can't go until you line up an alternative caretaker.

In such cases, the word "refusal" may mark you as someone who is not compliant. Many health advocates are now urging that doctors use the phrase "declined at this time," as well as providing the patient's reason.

In general, your doctor is on your side and their notes reflect the joint patient-doctor partnership to improve your health. But if you have cause for concern, or when these notes are being forwarded to a different MD, remember to take advantage of this new patient right.



Image: Freepik.com

A Family Affair

Every family experiences the death of loved ones – it’s part of the fabric of life. When FEN volunteers and siblings Mary Ellen and Russell Bates lost their mother while facing their dad’s Alzheimer’s diagnosis, they knew they were beginning an arduous journey.



Siblings Mary Ellen and Russell Bates, hiking years ago in the Sierras.

Russell describes:

“(Dad) had seen his own mother suffer the complete mental degradation of advanced Alzheimer’s and many years’ confinement in a nursing facility before her death. He was still articulate, funny, and in strong health, but he could see the changes happening and knew where things were heading... He called his kids together and let us know that he wanted to end his life. Mary Ellen and I and our two sisters were totally supportive of his wishes, but we knew of no resources to support our dad in achieving his goal.”

Russell, who is a commercial and TV director, took the opportunity to shoot a long video interview with his dad, Pete, during which his father looked back on his life and explained his philosophy of wanting to end that life happily and peacefully, surrounded by his loved ones.

Pete Bates’s process of self-deliverance provided him some peace of mind and allowed him to have special time with each of his children, but it was not without challenges. “His clear decision to reclaim control through self-determined death was a gift to all of us kids, but the process of his death was difficult and distressful,” Mary Ellen recalls.

When she later learned about FEN’s Exit Guide Program from a friend, she describes having two immediate thoughts: “If only this resource had been there for our dad,” and “I want to do this so that other loved ones don’t suffer the way I did.”

Thus began a new journey for the sister and brother. Mary Ellen trained to become an Exit Guide in

2021, became a Senior Guide, a *Chosen Death Forum* moderator, and presents workshops on EOL options.

Shortly after Mary Ellen began volunteering with FEN, she and Russell spent time at a family cabin in the Sierras. She remembers, “As we hiked trails rich with memories of family trips with our parents and grandparents over the years, I described how serving as an Exit Guide transformed the sadness and pain surrounding Dad’s passing into a force for good. I talked about how participating in FEN’s program enabled me to alchemize sorrow into uplifting purpose.”

Having wanted to get involved with RTD organizations for a while, Russell was inspired to connect with Final Exit Network after hearing about Mary Ellen’s experience. By that fall, he was volunteering as a coordinator, where he serves as the first point of contact for people inquiring about the Exit Guide Program.

Russell says he is grateful that he’s able to answer questions and connect people to FEN’s compassionate guides and educational resources about peaceful, painless exits.

“FEN’s work is indelibly impacted by the dedication, professionalism, and compassion of its volunteers,” says Executive Director Mary Ewert. “We celebrate the remarkable individuals who embody the spirit of volunteerism, and recognize that their efforts shape our world and inspire others to become involved.

“Thank you to Mary Ellen Bates, Russell Bates, and the more than 70 other volunteers who are at the heart of all that FEN accomplishes.”





Karen Ann Quinlan

21 yrs old
Alcohol / valium
4/15/75 - 5/11/85
10 yrs in limbo



Nancy Cruzan

25 yrs old
Car crash
1/11/83 - 12/26/90
7 yrs in limbo



Terri Schiavo

26 yrs old
Cardiac arrest
2/25/90 - 3/18/05
15 yrs in limbo

CONTESTED DEATHS – These three young women waited more than 32 years combined for peaceful exits because they and their families were not ready or equipped to choose a path to quality of life – not merely extending a heartbeat.

When quality trumps quantity, know when (and how) to say ‘No’

By *Althea Halchuck*
FEN Surrogate Consultant

In 1983, Nancy Cruzan’s car accident put her on life support for the next eight years. Her parents petitioned the US Supreme Court to remove her feeding tube, but were denied. However, in a landmark decision, the court ruled that competent adults had the right to refuse medical care under the US Constitution.

In December 1990, her family was finally allowed to remove her life support.

Nancy experienced a bad death by any measure.

In her op-ed, *The Long Death of Nancy Cruzan*, noted columnist Ellen Goodman claimed: “Her death did not come gently to any of the Cruzans. Nancy came to represent the unintended consequences of technology, the side effects of our best intentions, and the cruelty of our modern medical mercy. She came to represent something worse than death.”

Forty years later, people are still confused about their medical rights. Recently, a patient said she wished she did not “have to have” another round of chemo. The woman said she just wanted to be able to

enjoy this one last summer, but with chemo, she would be sick all the time, ruining everyone’s summer.

When asked why she thought she “had to have it,” the patient said her oncologist would be “upset” if she did not. She knew that the cancer was killing her, and more chemo would not do her any good. However, her family insisted that she needed to “keep fighting.”

I imagine what her summer will be like without chemo. She will be free to enjoy it

with a bittersweet poignancy, knowing it is her last. She can sit by the seashore, feel the sun on her face, breathe the salty air, and listen to the song of the waves. Rather than spending her summer dealing with the side effects of poisons, she can have quality in the time she has left. She can have heart-to-heart conversations while gently preparing her loved ones for her eventual departure, so no one has any regrets or leaves anything left unsaid.

Opting for the promise of summer rather than the rigors of chemo, she can create many happy memories that her family and friends will cherish long after she

*How we die will be the last
important decision we ever make.*

is gone. She can make the most of her time left by letting nature take its course.

The choice is a trade-off: less quantity of time, but often more quality. Most would describe that scenario as “a good death.”

In late January 2022, my sister-in-law was diagnosed with stage-4 cancer in her lungs, which metastasized to her liver and bones. At first, some medico said she was “terminal” and suggested “comfort care.”

Instead of meeting with a hospice team, oncology took the lead. Her oncologist “talked her into” the latest immunotherapy treatment, not a cure, but something to make him feel like they were keeping out of death’s grip.

Once she started the treatment in mid-February, he assured her and the family she would feel better and her appetite would return, maybe “in six to eight weeks.” Instead, the quasi-treatment only added to her suffering and delayed her going into hospice.

From diagnosis to death, it was two months. During those weeks, she was on infusions for a useless Hail Mary treatment, all of which robbed her and her family of precious time to talk about what mattered most.

Her final wish was to go to the beach and hug her grandkids, but the choice to have infusions robbed her of that simple pleasure.

As I write this, I hear news from an old friend of

*I hope I experience a peaceful death
at home, on my own terms,
surrounded by my loved ones.*

her husband’s passing of pancreatic cancer: “Since it had already metastasized, he/we opted for no oncology intervention ... it would only prolong the inevitable. He said, ‘I have been handed a death sentence, and I don’t want to be a guinea pig.’ He wanted, and I agreed to, home hospice care. On the 19th day after diagnosis, he peacefully passed.”

I hope that when it is my time to go, I will face it with the same courage and grace as my friends, and not chase illusionary treatments designed to extend my life without gaining any quality. His death was unexpected and tragic for this loving couple, but they faced the challenge head-on and spent his and their last days at home together; in my opinion, a good death.

Choosing the fork in the road as my friends did, I hope I experience a peaceful death at home, on my own terms, surrounded by my loved ones.

How we die will be the last important decision we ever make.

*Surrogate Consultant Althea Halchuck
can be reached at (978) 618-7150.*



Famed British broadcaster considers ‘Swiss option’

Dame Esther Rantzen, the renowned British broadcaster, has sparked spirited UK debate by publicly declaring her membership in Dignitas, the Swiss clinic known for assisting deaths.

Dame Esther, 83, could be set to follow the 650 Britons who have flown to Dignitas to end their lives legally. (Medical Aid in Dying is banned in the UK, with a maximum prison sentence of 14 years.)

She is currently having “miracle” treatment for stage-four lung cancer.

In December, Rantzen shared an interview on the BBC Today podcast about her thoughts on assisted death in Zurich, where it is legal. Her choice to join Dignitas stems from her desire to spare her family from witnessing a painful end, she said. Reflecting on life’s experiences and the loss of loved ones, she said her dog had a better death than any human she had known.

She explained, “I might buzz off to Zurich,” but admitted that if her family accompanied her, “the

police might prosecute them.” In England, Wales, and Northern Ireland, assisting suicide can lead to a 14-year prison sentence; in Scotland, it may be prosecuted as murder or manslaughter.

The Health and Social Care Committee is getting set to publish a report on assisted dying and suicide, following an inquiry launched in December 2022.

This study aims to explore diverse perspectives on this highly controversial issue.



Dame Esther Rantzen



More Good Endings

Reviews by Jim Van Buskirk

– Tom Preston, MD – *Doctor, Please Help Me Die* (2013)

The title says it all in this book by cardiologist Preston (who also served as End of Life Washington’s Senior Volunteer Medical Director) in conjunction with Janice Harper, a Seattle-based medical anthropologist.

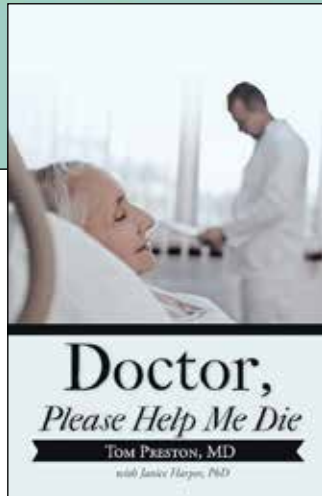
Even though it was (self-)published over 10 years ago, all of Preston’s impassioned arguments in support of Physician Assisted Dying (PAD) remain relevant. Offering many examples – court cases, movie representations, and personal experiences – he forcefully debunks the many excuses (religious, medical, and legal) against PAD.

He is especially unsympathetic to his medical colleagues, accusing them of shirking their responsibility for patient-centered care because of a combination of guilt, fear of adverse publicity, function-lust, financial incentives, social or professional imperatives or inhibitions, or religious or cultural prohibitions.

Refreshingly dogmatic, his succinct (150-page) manifesto ends: “Above all, the majority of Americans who support physician aid in dying on grounds of moral value should not remain passive while so many of our friends and relatives face extended dying with agonizing physical and emotional pain, helplessness and indignity.

“It is time to make your voices heard – in your physician’s office, in your home, and in your community. Do not go silent into that good night if what you ultimately seek is to go gently.”

FEN members will find his supportive words motivating to continue (or initiate) conversations with families, friends and – most importantly – physicians.



– Nikki Tate – *Choosing to Live, Choosing to Die: The Complexities of Assisted Dying* (2019)

Filled with important information leavened with many photographs and drawings by Belle Wuthrich, this is an excellent introduction to the topic of assisted dying.

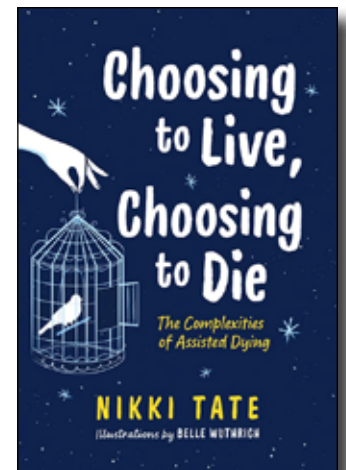
Inspired by the Canadian author’s own experience with her mother and geared toward teenagers, this straightforward resource is valuable for everyone.

Exploring the controversial issue from multiple, nuanced perspectives – including legal, religious, philosophical, linguistic, ethical, and historical – readers are encouraged to keep an open mind and to reach their own conclusions.

Tate emphasizes the importance of “finding the right words” to discuss these complicated issues. For example, she investigates the evolution of euthanasia, originally Greek for “good death,” which now refers to a doctor either directly causing or allowing death.

One chapter investigates the distinction between “extending life or delaying death” and notes the Dutch phraseology “termination of life on request.” In addition to many illustrative case studies, Tate references historical figures in the international right to die movement, like Jack Kevorkian, Thomas Preston, John Bodkin Adams, Ellen Wiebe, Philip Nitschke, and others. (I wish she had included Derek Humphry, though she does list *Final Exit* among her many useful references.)

An index and glossary add to the usefulness of this sensitive and straightforward contribution to the issues.



– Jim deMaine, MD – *Facing Death: Finding Dignity, Hope and Healing at the End* (2020)

Using stories from his 40-year career as a pulmonary and critical-care specialist, Dr. deMaine offers an important insider perspective on end-of-life options. Among the many topics he discusses are the

romanticized ideal of dying at home, contrasted with the reality of hospital; nursing home or other care facilities; dilemmas around honoring Advance Directives; the importance of building trust by listening; situations involving complicated ethics, and the role of

spirituality.

His empathetic conversational style renders challenging topics engaging, and this sensitive physician repeatedly interrogates himself: “Did I do the right thing?” Some of the many truisms from

Loving Choices, Peaceful Passing: Why My Family Chose Hospice

By Kathleen Vallee Stein • Book review by FEN Surrogate Consultant Althea Halchuck

Author Stein hooked me in her introduction, as she takes us on an intimate end-of-life journey, beginning with her father’s decision to stop the cancer radiation treatments that were killing him, and ending with his peaceful passing in the arms of his loving family 29 days later.

Walk in Kathleen’s shoes as she candidly and honestly leads us through her family’s emotional and often painful end-of-life journey and the difficult decisions they had to make.

“But first,” she writes, “and most difficult, was accepting that he was dying and releasing him from the hospital’s culture of cure at all costs.” She says acceptance and enrolling him in hospice is what brought them peace.

Kathleen holds nothing back as she talks about her difficult relationship with her stern father while she was growing up, and her siblings, who left all the heart-wrenching and exhausting caretaking to Kathleen and her sister, Anne.

She lays bare her struggles with her dysfunctional family, and in doing so, she shows us that dysfunction is the new normal. While reading her story, it is easy to imagine that every family has disorder to some degree and that, ultimately, someone in the family needs to step up to care for aging parents.

As Kathleen says, “I stepped up and did what

had to be done. My dad lived his last days in the comfort of his own home, cared for by my sister and me. It wasn’t easy, but we did it.”

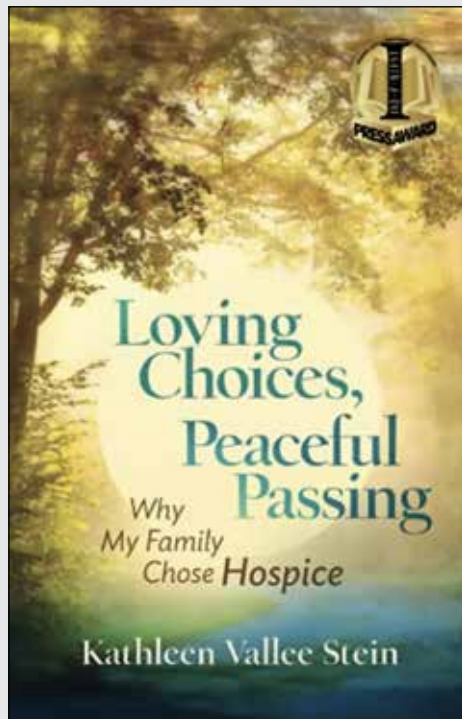
This is a must-read for anyone contemplating hospice – learn the family commitment and fortitude it requires in bringing someone home to

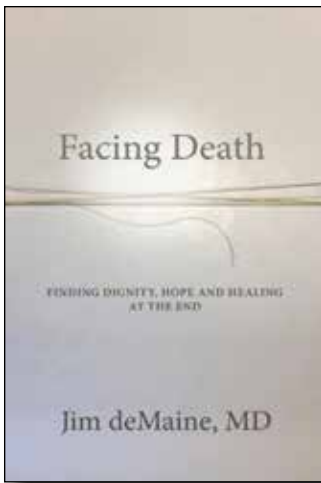
die with the help of hospice. The journey is fraught with daily challenges, much heartbreak, and many tears, but they discover the rich experience gained when loved ones say what’s on their hearts and relate what matters most at their end of life.

This memoir is not a weepy tale, but richly demonstrates the promise of hospice; it’s not about giving up, but making the most of the time you have left. It is mostly a tale about selflessness, forgiveness, of caring for Dad, who faced his final days with courage “and remained a gentleman to the end,” writes Kathleen.

A testimonial from a reader said it best: “It’s hard to imagine a more personal memoir about a daughter’s relationship with her father on his passage through hospice. (The author) shows her pain, conflict, and strength as he shows her his trust and love. This book is more than how-to; I felt I could use her own fortitude and spirit to help me through hospice.”

This book is a rare gift.





this dedicated medical professional include:

- *Discussion and shared decision-making around death require great sensitivity.*

- *There is far more (medical) knowledge available than we can absorb, and it continues to expand exponentially.*

- *We may listen, but we don't know the right*

questions to ask.

- *More important than completing any document is designating your Health Care Proxy.*

In the chapter “Assistance in dying – pros and cons,” he explores MAiD and Voluntarily Stopping Eating and Drinking (VSED). In “Reflections,” deMaine offers, “I learned to expect the unexpected in my medical practice, dull moments were few. In these eclectic reflections I touch on the COVID-19 pandemic, common and uncommon diseases, the discovery of a previously unknown syndrome, health-care costs, and strange things that happen in hospitals that you never hear about.”

Supplementing this volume of heart-filled wisdom is the appendix of FAQs, offering links to many valuable resources.

– Lee W. Hansen – *Forgetting and Forgotten: Dementia and the Right to Die* (2023)

This valuable new book is simultaneously a cautionary tale and a call to arms. The author, a University of Wisconsin-Madison professor emeritus in economics, uses his experience watching his vibrant wife’s descent into dementia and his expertise in advocacy to create an important contribution to the conversation about dementia patients’ end-of-life options.

Relying on his daily journal entries, he chronicles Sally’s 10-year trajectory from 2006 until her death in 2016.

Their heartbreaking journey offers remarkable rewards for the reader. Carefully observed details straightforwardly describe a clear picture of Sally’s deterioration, including depression, repeated falls, alcohol abuse, cognitive decline (distinguishing

between dementia and Alzheimer’s), agitation, paranoia, and the challenges of multiple care facilities, medical professionals, and medications.

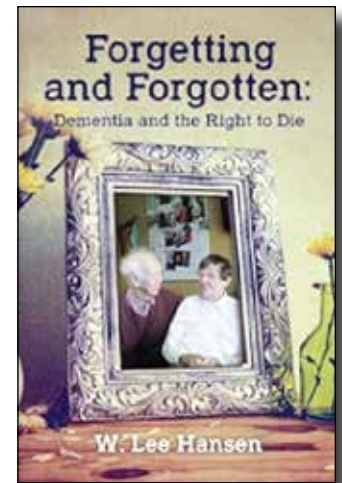
While emphasizing that each person’s experience is unique, Hansen’s willingness to share his intimate observations is a profound gift.

Although Sally eventually died peacefully, her loving husband remains bitter: “We fought a long fight together for the right to die with dignity, a right that was not granted her.”

Fourteen images of Sally’s life, as well as her obituary and a description of her many accomplishments lovingly memorialize this amazing woman.

The book’s final third offers a toolbox of helpful information about how to advocate for oneself, one’s loved ones, and more broadly, to change the current legal/medical situation regarding right-to-die options specific to dementia. A few minor mistakes mar the otherwise impeccable guidance, including confusing the roles of Final Exit Network and Exit International.

Kudos to Hansen for employing his painful personal experience to produce a poignant memoir.



‘There at the End: Voices from Final Exit Network’

This anthology of personal stories describes the often heartwarming and sometimes heart-breaking experiences of volunteering with FEN.

This year marks the 20th anniversary of FEN, an outgrowth of Derek Humphry’s Hemlock Society. This collection lifts the veil on FEN’s volunteers, documenting the necessity for more visibility and communication about the complicated and controversial issue of one’s right to die.

Selections from the FEN magazine, interviews, profiles, and original first-person narratives coalesce into a never-seen-before portrait of the committed and compassionate MDs, Exit Guides, other volunteers, members, and clients as they support FEN’s one-of-a-kind mission.

SKY'S THE LIMIT!

FEN outreach soared in 2023

Photo: Chris Niver, Andes Mtns.

By Jay Niver, FEN Editor

More than 2,600 people last year received the message about the vision, mission, and work of Final Exit Network thanks to both in-person and online presentations by members of the FEN speakers bureau.

What's more, nearly 14,000 Internet surfers visited *The Good Death Society Blog* to read its 54 posts on a wide range of right-to-die and end-of-life subjects.

Both outreach efforts marked all-time highs under the stewardship of Melanie Raine, who co-manages both the blog and speakers bureau.

"Last year was significantly the best year to date in total blog views, visitors and subscribers," she reports. "And the blog's impact goes beyond people reading it in real time."

Blog posts are reused on FEN's Facebook, Twitter, and LinkedIn pages, and many new subscribers post a link on their own websites and recommend the blog. "It all multiplies the accumulative influence of the original posts," says Melanie.

In the fourth quarter of 2023, *The Good Death Society* had 770 subscribers – people who signed up to be notified whenever a new article was posted. In

July, the blog averaged 132 views each day, though the average for other months was typically around 80.

FEN speakers bureau members personally presented and/or Zoomed programs originating in 19 states last year. When the COVID pandemic began in March 2020, live presentations gave way to online meetings, and most organizations and venues now use hybrid formats to conduct gatherings.

FEN speakers participated in 68 events, three of which involved more than 100 attendees. Some of the programs were videotaped and/or audio recorded for subsequent exposure to an audience much larger than in real time. In addition, potential viewers and downloads from 2023 podcasts, radio shows, newspaper articles, Facebook Live, and television appearances hugely magnified the impact of FEN's outreach initiatives.

Among the states that hosted FEN presentations, California was the most active with nine events held there. New York was second with six programs while Oregon had five; Colorado and North Carolina each hosted four.

Word is getting out, and the sky is the limit.



Screen star Rigg recorded plea for MAiD before dying

Shortly before her death in September 2020, British film and television star Diana Rigg made an impassioned case to legalize MAiD in a message recorded shortly before her “truly awful” and “dehumanizing” death from cancer.

The actor’s statement calling for a law that gives “human beings true agency over their own bodies at the end of life,” published in December, adds to the ongoing, increasing UK debate over assisted dying. MPs are expected soon to publish their recommendations to the government. (See related story on page 9.)

It was released by her actor daughter, Rachael Stirling, who promised the star of *The Avengers* 1960s TV series and *Game of Thrones* that she would share the message with the public.

In the recording, Rigg says: “They don’t talk about how awful, how truly awful the details of this condition are, and the ignominy that is attached to it. Well, it’s high time they did.

“And it is high time there was some movement in the law to give choice to people in my position. This means giving human beings true agency over their own bodies at the end of life. This means giving human beings political autonomy over their own death.”

Rigg taped her statement on a cassette recorder given to her by her son-in-law, musician Guy Garvey.

Vividly describing the last weeks of her illness, she says: “I have cancer, and it is everywhere, and I have been given six months to live. And I’m not frightened of describing the least attractive aspects of my condition: The fact of the matter is, I have lost control of my bowels. This, to me, is quite the most dehumanizing thing that can happen.



Diana Rigg

“Yet again we found ourselves in the bathroom this morning, my beloved daughter and I, half laughing and half crying, showering off together, and it was loving, and it was kind, but it shouldn’t happen. And if I could have



Diana Rigg cut quite a figure as Mrs. Emma Peel in the 1960s TV series *The Avengers*.

beamed myself off this mortal coil at that moment, you bet I would’ve done it there and then.

“Any palliative nurse will tell you, in the end, patients often starve themselves as a means to an end. The body becomes weaker, the organs shut down. It’s not that they want to die that way. It’s how they take control.

“Nobody speaks about this.” They talk about the pain and the dread, she says, but not the awful details of the condition.

Explaining why she is recording her views, Rigg – who was diagnosed with lung cancer in March 2020 and died at 82 – says: “I’ve always spoken out. I spoke out when I was very young, doing *The Avengers*, and learned I was earning less than the cameraman. I spoke for peace in Vietnam, in Northern Ireland. I marched for peace in Iraq. I stood up for what is right. I speak my mind. I always have.”



THE BACK PAGE

A COMPENDIUM OF RIGHT-TO-DIE WORLD NEWS

Cuba

In late December, Cuba became the second country in Latin America and the Caribbean to authorize euthanasia, following Colombia.

The Communist-run country's National Assembly passed the measure as part of legislation updating the nation's legal framework for its universal and free healthcare system.

At Havana's Institute of Oncology and Radiobiology, the country's leading cancer center, Dr. Alberto Roque welcomed the measure and said it established the "legal framework for future euthanasia in any of its forms, that is, active euthanasia or assisted suicide."

There was little mention in Cuba's state-run media that the government would approve the practice, and no public debate, though Dr. Roque said that would change as regulations are drawn up.

Canada

Medical Aid in Dying (MAiD) for those with mental illness may become legal in March in Canada as part of a law that has seemingly divided the country.

It would make Canada one of the very few countries to permit MAiD for people whose only medical condition is mental illness. Jason French, a man who has tried to kill himself twice, told the *New York Times* he backs the law, saying he "can't keep suffering."

However, critics contend the legislation is indicative of inadequacies in Canada's healthcare system, particularly psychiatric care.

The country legalized MAiD for terminally ill people in 2016, and the law was expanded in 2021 to include other severe illnesses. The 2021 revision excluded mental illness for a two-year period, until last March 17. However, parliament delayed implementation and may do so again, so expansion might not take effect as scheduled.

In 2022, 13,241 Canadians opted for assisted death, a 31.2% increase from the year before.

United States

- **Missouri** is joining the list of states to consider allowing doctors to assist in their patients' deaths.

The state's bill was pre-filed in December by a Democratic lawmaker, Ian Mackey, who said the

issue was brought to his attention through Dr. Steven Teitelbaum, whose wife was diagnosed with ALS in 2022.

Dr. Teitelbaum and wife Marilyn moved to Colorado, where MAiD is legal, so she could die as peacefully and pain-free as possible, said Rep. Mackey.

As lawmakers prepare to take up the legislation, Mackey added, "There's a reason we call it death with dignity, and there's a reason we call it end-of-life care."

Gallup polling indicates that Americans have consistently favored assisted dying since Gallup first asked about it in 1996. Gallup's 2023 numbers show that 53 percent of Americans think MAiD is "morally acceptable," but 44 percent think it is "morally wrong."

- **Vermont** has reported that its number of MAiD deaths more than quadrupled in the last two years.

There were 84 "reportable events" between July 1, 2021, and June 30, 2023, though the report later clarified that 72 of those were actually via MAiD, while the others were caused by the underlying disease or another cause. Seventy-three percent of those who chose assistance did so because of cancer.

In contrast, the state's previous report (issued in January 2022) revealed 17 assisted deaths. There have been 203 deaths since MAiD was legalized in 2013. However, per law, Vermont lists all such deaths as "natural" on a death certificate and notes the cause as the underlying disease.

State lawmakers are continually looking to loosen the reins. In 2022, they legalized "telemed" MAiD appointments, which allowed a physician to sign off on a patient's request without meeting face-to-face. Last May, the state passed a bill allowing non-residents to come to Vermont for MAiD.

United Kingdom

A UK government petition to hold a parliamentary vote on assisted dying passed 12,000 signatures in January and will receive a government response.

It calls for UK lawmakers to allocate parliamentary time for MAiD to be fully debated in the House of Commons and to allow MPs a vote on the issue.

High-profile figures such as Dame Esther Rantzen and Dame Diana Rigg have brought media attention to the issue in recent months, all of them urging MPs to recognize the need for a compassionate MAiD law.



CT woman uses MAiD in VT after suing for access

State drops its residency requirement

A Connecticut woman who fought for expanded access to Vermont’s Medical Aid in Dying (MAiD) law – despite its residency requirement – used that option there on Jan. 4, an event her husband called “comfortable and peaceful,” just as she wanted.

Lynda Bluestein had terminal cancer and ended her life by taking prescribed medication.

Her last words were, “I’m so happy I don’t have to do this (suffer) anymore,” her husband, Paul, wrote in an email that Thursday to Compassion & Choices, which shared it with news media.

The organization filed a lawsuit against Vermont in 2022 on behalf of Bluestein, and Diana Barnard, a physician from Middlebury, CT. The suit claimed Vermont’s residency requirement in its MAiD law violated the US Constitution’s commerce, equal protection, and privileges and immunities clauses.

The state agreed to a settlement last March that allowed Bluestein to use the law to die there. Two months later, Vermont made the same option available to anyone in similar circumstances, becoming the first state in the country to change its law to allow terminally ill people from out of state to take advantage of it to end their lives.

Oregon had earlier permitted cross-border use of MAiD, under a legal settlement, and state lawmakers passed changes to their statute last July, removing its mandate that only Oregonians could access assisted dying.

“Lynda was an advocate all the way through, and she wanted access to this law and she had it, but she and everybody deserves to have access



Lynda Bluestein

much closer to home because the need to travel and to make arrangements around the scheduling to come to Vermont is not something that we wish for people to have,” Barnard said.

Barnard said it’s a sad day because her life came to an end, “But more than a silver lining is the beauty and the peace that came from Lynda having a say in what happened at the very end of her life.”

