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How do you explain that you want to bring your life to a close while you are still on good terms with it?

By Ruth Dixon-Mueller – June 14, 2023

January 2023. A public service announcement in Final Exit Network’s magazine a while back pictured Switzerland and urged us to “Visit for Vacation, Not to Die.” It made me laugh. But here I am, about to visit Switzerland – *not to vacation, but to die.*

As a devoted FEN member, I’m feeling a bit disloyal.

Why Switzerland? It’s one of six choices listed in FEN’s guide to “Options for Hastening Death ...” But the other five don’t work well for someone in my situation.

For one thing, I’m not dying yet, so I’m

not eligible for Medical Aid in Dying (MAiD) in California. Nor am I being treated for a potentially fatal condition, so stopping a therapeutic medical intervention is moot.

Voluntarily Stopping Eating and Drinking (VSED) is not ideal for someone in relatively good health – for an 85-year-old, that is. And because I’m not yet facing “intractable suffering or “a loss of self-hood through dementia,” I don’t meet the conditions for FEN’s Exit Guide Program either.

Self-deliverance with the help of the *Final Exit* book and website is a possibility, but not **SWISS OPTION – continued on page 2**



**A FEN
pillar
uses –**

**a healthy
SWISS
OPTION**

Ruth Dixon-Mueller

SWISS OPTION *continued from page 1*

in my senior-living residence where a suicide prompts official investigations and emotional distress. Nor do I want to end my life alone in a hotel room. That leaves the Swiss. But would they accept me? I was determined to find out.



Of the two Swiss organizations listed in FEN's guide, [Dignitas](#), near Zurich, is the better known. It costs about \$242 USD to join. A member who is of sound judgment and physically able to self-administer the MAiD drug may request an accompanied suicide "in the case of medically diagnosed hopeless or incurable illnesses, unbearable pain or unendurable disabilities."

Dignitas asks for a personal, signed and dated letter that explains the reasons for your request and current health condition; a biographical sketch; and one or more recent medical reports, plus two or three older ones with case histories, diagnoses, treatments, and prognoses. A Swiss physician decides your eligibility based on your written request, medical reports, and two face-to-face meetings.

For those who get the "green light" and take advantage, payments amount to about \$11,600 for the entire process, including consultations, MAiD, cremation, and death certification. There would be no green light for me without a serious medical indication.

[Pegasos](#) is a newer and smaller Voluntary Assisted Dying (VAD) organization based in Basel. They promise a more flexible approach with less reliance on medical issues or opinions. Their homepage assures us that "Pegasos believes it is the human right of every rational adult of sound mind, regardless of state of health, to choose the manner and timing of their death."

You're invited to become a supporter (\$110) and, if you wish, fill out an online application form with your reason for requesting VAD, biographical and health-related information, and a preferred date.

You must scan and upload personal records (passport photo, birth certificate, marriage or divorce records, proof of legal residence, and a brief medical

history). Queries to contact@pegasos-association.com will guide you through if you need help. A bank transfer to Basel of 5,000 Swiss francs (about \$5,500) starts the review process.

The day after my bank wired the funds, an email popped up: "Funds received. Thank you very much!"

Eight days later, my cell phone chimed.

"Hello, Ruth?" said a friendly male voice. "I'm calling from Pegasos. We want you to know that the date you requested for your VAD is confirmed, June 15th."

"Are you sure?" I gasped. "Who am I talking to?"

"Yes, I'm sure," said the voice. "This is Ruedi. I'm the president. We look forward to meeting you."

It wasn't quite this easy, of course. Filling out the application requires serious thought. A particular challenge for me was, "Reason for applying for VAD (up to 300 words)."

How do you explain that you want to bring your life to a close while you are still on good terms with it? You are aware that your body will not oblige you much longer, and you are determined not to relinquish your independence? That flying to Switzerland for a quick and peaceful death is, in your view, a perfect way to end your life story?

The application form explains that a person applying for VAD at Pegasos does not necessarily need to be seriously ill. Nevertheless, you are asked to describe any current diagnoses you may have, plus physical limitations on your movement, current treatment regime (if applicable), and current medication. A medical document with diagnoses and current medications is required if you have had, or currently have, a serious illness. I was asked to submit a short documentation of my age-related concerns, simply as an assessment of my situation.

The necessity to supply this information was explained: The staff and MD/lawyer looking into your situation have to know how they can best assist you (travelling is often not easy for ill people; recommendations from experienced professionals are very helpful). With your information, Pegasos also finds out what kind of assessment is needed in your



The hardest part is telling people that your cheerfully announced plans not to outlive your life are no longer hypothetical.

case. They will connect you with the independent medical physician in Switzerland, which establishes this together with you. Additionally (and very important), Pegasos shows to Swiss authorities that they evaluate your full situation carefully.

Pegasos requires a second bank transfer of 5,000 Swiss francs following the confirmation of VAD, along with a formal authentication of your birth certificate (including parents' names) from the issuing agency. If a newly issued birth certificate is almost impossible to get, however, it does not make a timely VAD impossible.

You must tell Pegasos whom you will bring with you (with contact information) for identification purposes and to handle a few details after the event. If you have absolutely no one to accompany you, discuss this with Pegasos. This will make everything a bit more difficult, but not impossible!

Once everything is confirmed, you will receive a checklist reminder of what to take to Basel, including the original documents you uploaded, and what to expect once you arrive.

And, so the countdown has begun. The hardest part is telling people that your cheerfully announced plans not to outlive your life are no longer hypothetical. They are real, the date is set, and it's time to say goodbye.

• • •

June 14, 2023. Nestled in the hills not far from Basel, my hotel faces the arched gateway to a medieval town with broad plazas; narrow, crooked streets, and outdoor restaurants. I've been exploring the town and drinking cappuccinos with my nephew and his wife, who are here to identify me for legal purposes and share my last days.

This afternoon, the doctor came to the hotel to explain VAD and its follow-up (authorities, coroner, certification), answer our questions, and obtain my signature (power of attorney to pick up the medication in my name). Tomorrow morning, a car will pick us up for the short drive to Pegasos. I'll meet with Ruedi (who joined us for wine and tapas tonight) and a staff member, to present my documents and review the process once again.

When we're ready, the doctor will prepare me to self-administer sodium pentobarbital intravenously.

"Don't worry," he assures me, "it will take only a few seconds before you slip into a peaceful sleep."

I imagine settling into the plump bed pillows with legs stretched out, closing my eyes, pressing the button, and soaring on a handsome winged horse into a darkening sky.

How perfect is that?



Ruth Dixon-Mueller, 85, was born in Toronto and showed early signs of rebellion by attending Art College rather than the university; marrying Ruben Dixon, her high school sweetheart; and moving as a new bride to California.

Ruth thrived in the tumultuous years of the 1960s in Berkeley, earning a BA, MA, and PhD in sociology at the University of California. Though her marriage did not survive, her academic and early feminist aspirations blossomed.

In 1970, UC Davis hired her (as an affirmative action, according to Ruth), where she progressed to full professor and department chair, teaching there for 18 years.

With a special interest in South Asia, her demographic- and policy-based research, writing, and consulting activities spanned themes of women's employment in developing countries, marriage formation and dissolution, fertility and family planning, the sexual and reproductive health and rights of girls and women, and the politics of population policies.

She authored five books and numerous articles for professional audiences worldwide.

Ruth resigned from UC Davis in 1988. In 1992, she left a 15-year marriage to Swiss-born Martin Mueller to move to Costa Rica with a friend. She lived there for 18 years, growing coffee for the local market and organic pineapples for export. Still writing and consulting, she returned to California in 2010.

Following her 2017 book, *Passing On*, that analyzed concepts of fairness in inheritance bequests, in 2021 she published an [essay on end-of-life choices](#). Her advocacy for sexual and reproductive rights and the "right to die" carried through to the end.

Ruth leaves friends in many places as well as her sister, five nieces and nephews and their partners, children and grandchildren in Canada and Australia.

Audits bring recognition

– *Grant writing may bring new funding* –

FROM EXECUTIVE DIRECTOR MARY EWERT



I must open by sharing the sadness I felt when I learned of board member Ron Liesemer's death.

Over dinner at my first FEN board meeting in 2019, I enjoyed a cordial chat with Ron, who made me feel welcome and at home. Over the years, my main interactions with him were through the finance and the strategic planning committees. In both instances, Ron brought his business experience to the table along with a collegial style that won the cooperation of all, even when some strongly held views were not adopted.

I'll miss Ron greatly, and I send my condolences and sympathy to his family. (See story on page 7.)



As we head toward the July board meeting in Chicago, we can celebrate our many accomplishments over the past year.

With one audit successfully completed, and a second soon underway, FEN has earned the Candid Platinum Transparency 2023 Seal, displayed on our website. We've submitted paperwork for the Charity Navigator Seal and hope to receive that soon.

Thanks to our communications consultant, Christina Mancini, for submitting these applications and getting the job done.

Our fundraising consultant, Patrick Youngblood, just submitted a grant application to a new funder who was surprised and intrigued to learn about FEN's work. The proposal we submitted would fund research around dementia-related end-of-life options, to improve the lives of older adults. While there is no guarantee this application will result in an award, we're thrilled to be reaching beyond our strong supporters to find additional avenues of income and support.

Patrick will be submitting additional applications to

other potential funders during the coming year.

Our Speakers Bureau manager, Melanie Raine, is providing additional training and quarterly opportunities for our presenters to exchange tips and ideas. In the coming year, we're focused on outreach to groups that might not know us.

If you have contact with organizations that provide information and support to patients (ALS Association, American Parkinson Disease Association, groups serving minorities, and so forth), fill out

the form on our website (under Services – Speakers Bureau), and Melanie will follow up with you.

If you are a FEN member with questions about your membership, you have most likely met Heike Sanford, who now wears the title of member services coordinator. Heike, who has been with FEN for over six years, manages our database and processes memberships and donations, including those made online through the FEN website.

It's easy to renew and donate through the website, and we hope more of our supporters will adopt that paper-free method. If you have questions or need assistance, feel free to contact Heike at heikesanford@finalexitnetwork.org.

Looking ahead to FY2023-24 our goals include: strengthening backup support for our wonderful staff; expanding relationships with other right-to-die organizations; fine-tuning our social media presence and outreach; and implementing an aggressive communications campaign. All this is done, of course, in support of FEN's core Exit Guide Program. It's why we exist and why we attract dedicated supporters.

I invite you to join me in renewing and expanding your support.





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

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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](#)

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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.

Chosen Death Forums gain momentum

By Deborah Alecson, FEN Member

Final Exit Network is offering a monthly online event, the Chosen Death Forum (CDF), for members. This is a Zoom opportunity for like-minded people to connect and talk about end-of-life options.

A pilot CDF was in October 2022, and the number of participants and facilitators has grown steadily. The forum is the first Monday of the month, 3 p.m. Eastern time. While a facilitator is assigned for break-out sessions, they are participant-led discussions that last 60 to 90 minutes. We try to have no more than 15 in a break-out room, to preserve a sense of intimacy.

Rules and guidelines are spelled out when you sign up, and repeated before the session begins. Some rules protect confidentiality and privacy – such as not disclosing participants' names or what they express – and to create an atmosphere of trust, such as keeping one's camera on (but recording is prohibited).

I have facilitated from the beginning and can report that we have sincere and knowledgeable participants

who often give great thought to topics that deal with end-of-life options, for themselves and their loved ones.

Conversations extend to social concerns regarding a chosen death; the realities of MAiD (medical aid in dying) where it is legal; how to talk with loved ones regarding our own wishes (and what to do if those who care for us cannot honor them); as well as thoughts on grief, especially anticipatory grief, that can come with a chosen death.

What we emphatically do not discuss are: specific plans to hasten death; methodologies for doing so; and equipment or sources. This is not a how-to discussion.

We are fortunate to have the technological support of Lily Chambers. Without her expertise, the CDF would be just a concept. The facilitators do meet with FEN Executive Director Mary Ewert, where we support one another in efforts to have an open, meaningful discussion for everyone.

Members are invited monthly to sign up for forums.



What can you do to protect your family members?



The GRUMBLING STATE OF ELDER-CARE FACILITIES

By Janis Landis, FEN Board Member

On May 3, 2023, relatives got quite a surprise when they went to visit a family member at a Lincolnshire, IL, nursing home. There were literally no staff on the premises. The patients – all frail and incapacitated by dementia and/or physical ailments – had been left to fend for themselves.

Unusual, perhaps. But patient neglect and abuse is becoming alarmingly prevalent at long-term care facilities.

Being a member of FEN means you have proactively sought to protect yourself from being involuntarily subjected to this. But there are situations where you or a family member may require such care. You may have a relative who chooses to stay in a care facility rather than cut short their life. Accidents or sudden, severe illnesses (such as strokes) may mean you are not physically capable of self-deliverance.

So, it is important to understand why this is happening and what you can do about it.

The biggest contributors to the problem are intertwined: Baby Boomers are the first generation to have extensive medical coverage, often including long-term care insurance. In turn, this massive amount of money has resulted in virtually all nursing homes becoming for-profit businesses run by private investors.

Predictably, a research team at Case Western Reserve University found that 64 percent of nursing

home residents received aggressive treatment in their final 30 days. A quarter underwent cancer treatment: surgery, radiation, chemotherapy.

Profits are further enhanced by cutting staff pay and benefits; reducing staff size; and decreasing the quality of amenities, such as food and recreational activities, etc.

What can you do to protect your family members in a nursing home?

- The most important first step is to research available facilities. If looking for a site with skilled nursing care, be sure to choose a Medicare-certified center.

Senior care centers are either “Medicare-certified” or “private-pay” facilities. In short, a Medicare-certified senior care center has met Medicare’s minimum requirements for patient care and management, including administration, clinical services, standards of excellence, and more. As a result, they can accept Medicare as a payor for some or all expenses incurred by the patient.

- Check online resources.
- Check official Federal Medicare Evaluations.
- Find Providers: [Compare Care Near You](#)
- Read customer reviews.
 - Google, Yelp, Facebook can all be helpful in getting feedback from patients and their families.

- Visit facilities.
 - Look around, observe patients in common areas and dining hall. Look at cleanliness of rooms, interactions between patients and caregivers.
- The second-most important activity is staying in close touch after a family member is admitted. Talk to staff, let them know you are aware and involved.
- Be adamant about ensuring staff honor advance directives. Do not get guilted into aggressive treatment or lured into expecting unrealistic improvements.

Promptly report abuses:

- Medicare Fraud

[Reporting Medicare fraud & abuse](#)

- State Nursing Home Licensing Agencies

Each State issues licenses that allow nursing homes to operate. They have procedures for reporting abuse.

As an example:

[Nursing Home Complaint Form | New York State Department of Health](#)

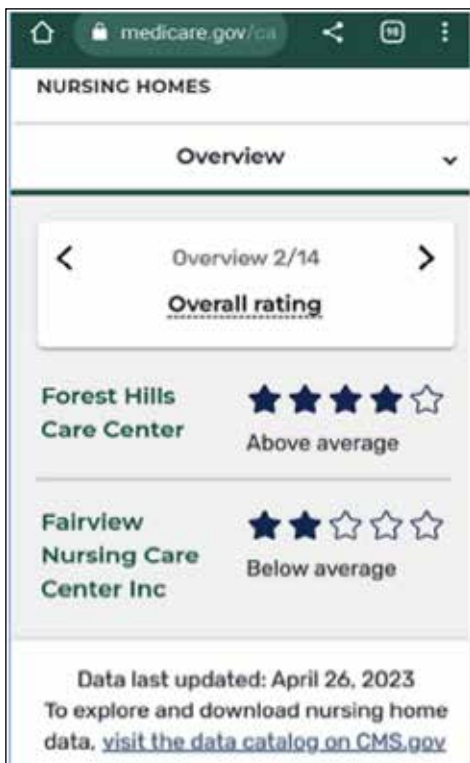
- Use your FEN membership resources.
 - FEN will assist you at no cost in ensuring that the patient’s Advance Directive is honored.
 - FEN attorneys will provide litigation services

to ensure fulfillment of contract requirements.

– FEN will work with a local attorney to file a wrongful prolongation of life lawsuit if a patient is subjected to un-approved medical treatment that extends suffering.

If you have had problems with nursing homes, or any extended-care facility, we’d like to hear about it. Please email us

at info@finalexitnetwork.org.



Here’s a sample of Medicare nursing home evaluations for one zip code.



FEN VP dies unexpectedly



Ron Liesemer

Final Exit Network’s Acting Vice President Ronald Liesemer died unexpectedly June 3 while moving to Oregon to be closer to his family. “Ron,” 85, and his wife, Karen, joined FEN in 2006, and he had served as a board member since 2017.

Ron was involved in the right-to-die movement for more than 20 years and sat on Compassion & Choices Capital Region Board of Directors. On FEN’s board, he chaired the research committee, sat on the executive and finance committees, and was instrumental in helping to devise FEN’s strategic plan.

Ron’s career led him to become a high-profile voice in the plastics recycling industry. In the 1980s, he managed the Mylar® polyester film business for DuPont Europe. In the ’90s, he created and led the organization that made plastics recycling a reality in the United States.

In 2020, Ron was included in “Plastic Wars,” an episode of the PBS *FRONTLINE* documentary series.

An environmentalist at heart, Ron once testified before a congressional committee on behalf of Sleeping Bear Dunes National Lakeshore, on the banks of Michigan’s Upper Peninsula. That hearing and legislative effort eventually led to the establishment of the 32,000-acre Sleeping Bear Dunes Wilderness – the first wilderness protection act passed by Congress in five years.

“I had the good fortune to work with Ron on the FEN board,” recalls former president Janis Landis. “His science background was an important skill in developing our strategic plan and assessing various proposals for exit methods. He brought a compassionate lens, as well as a scientific one, to all our deliberations.

“His humanity and dedication were an inspiration to all of us.”



The gifts that generous members and friends bequeath to FEN upon death are a major 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.

UP IN SMOKE NO MORE

*The first of a two-part series
on alternative options
for honoring and disposing
of the dead.*

Living people bit the dust with departed ones when heavy smoke with human ashes clouded San Diego after a 2018 crematorium accident.

By Jay Niver, FEN Editor

Thirty or 40 years ago, we would have celebrated that our US obsession with costly, wasteful, elaborate funerals (that made families feel good and morticians smile) was giving way to the more-reasonable option of cremation.

In 1970, only 5 percent of America's dead were cremated. Last year, it was almost 60 percent. It makes sense, since many cemeteries are now full – *no room to bury Grandpa*. In many cities, open land is scarce, and there's little motivation to sink coffins in ground that real estate moguls can develop far more profitably than selling even grossly over-priced plots.

• • •

It's no longer a question of the conventional US funeral – with embalming, public viewing, elaborate caskets, liners, vaults, and a Cadillac hearse procession. That ritual was dying in 2015 when cremation first out-numbered “the traditional way.”

Now we have many more ecologically friendly (and economical) options than just incinerating bodies to produce an urn of ashes.

One way is “alkaline hydrolysis” – using water instead of fire to arrive at the same end (but leaving almost a third more cremated remains than burning).

Another way is a “green” or “natural” burial – no embalming or vault, and no impervious container. Shrouds, caskets, and urns are biodegradable and non-toxic. The *dearly departed* return quickly to the earth and Mother Nature.



Hunter Beattie's aquamation machine lets clients choose water over fire to create their remains.

Hunter Beattie of Hillsborough, NC, is in the vanguard of those using new cremation technology. He and others call it “aquamation” or other varieties of *(add adjective) cremation*. “If I used ‘alkaline hydrolysis,’ I’d be out of business,” he says.

Beattie is a candid, straight-talking but sincere EOL provider who represents the new era of funeral professionals. His business, Endswell Aquamation, embraces America's changing view of what constitutes respectful, compassionate care for lost loved ones – no matter what the “funeral” may look like.

He has one of about 30 aquamation facilities in the country. By contrast, there are some 3,400 crematoriums used by America's 22,000 funeral homes.

Alkaline hydrolysis uses water, alkaline chemicals, and heat to accelerate natural decomposition, leaving bone fragments and a neutral liquid called effluent. The decomposition that occurs in the process is the

same as burial, just sped up dramatically.

Aquamation takes place at 200-300 degrees; fire cremation at 1,400-1,500. Beattie has encountered two religious groups who voiced concern about burning remains: some in the Jewish community, who associate it with the Holocaust, and various Christian denominations “who liken it to hell and damnation,” he says.

Using water to dissolve tissue (not incinerate it) seems like a gentle process, but skeptics wonder what happens to the leftover liquid: “Is Mom dumped down the drain?”

The effluent is sterile, with no tissue or DNA left after the process. It is discharged with all other wastewater and is a welcomed addition to city water systems.

A body’s bones still remain, just as with fire cremation. Both processes pulverize them into coarse dust, to be added to the ashes returned to the family.

Beattie offers a one-price option for clients, far below a typical funeral and less than a usual cremation. There are no hidden fees for services or add-ons. A basic urn is included, but customers may choose from an assortment of artisan urns in his one-of-a-kind gallery that features crafted creations.

“I saw the urns that are mass-produced in China with an American flag,” he says. “That wasn’t right.” He offers unique containers made from feathers, horse hair, sheep – many created by regional crafters.

While technically not a “funeral home,” Beattie hosts viewings of the deceased and shrouding ceremonies prior to aquamation. “We don’t have pews and *Reader’s Digest*,” he says.

“Some people come in, and they’re all business. They sign a contract; they’re in and out,” he adds. “Others want to talk for hours ... It’s a profound experience.”



Anne Weston created and runs the Green Burial Project, also based in Hillsborough. She’s more than just an advocate for natural interment – she’s almost a walking resource for anything death related.

“People need to know they have a choice,” she says. “In general, you will save money on a green burial over a conventional one.”

With no cost for embalming, or a casket and a vault – or, if you wish, no elaborate “celebration of life” orchestrated by a funeral director – a natural burial can save money. That said, the cost for a plot may be more, since conventional cemeteries inter over 1,000 bodies per acre, and green burial grounds do 100-300 – *preserving the environment is their goal*.

Consumers who spend \$2,000 to \$7,500 on an



Looking up!

Things look good for green burials and other environmentally friendly alternatives to the customary US funeral or cremation. (Photo courtesy of Heartwood Preserve, a natural cemetery and conservation sanctuary near New Port Richey, FL.)

exquisite casket can spend almost nothing on a green burial – just wrap your loved one in a favorite blanket or quilt. It will biodegrade, just as a simple pine box (which vendors increasingly are providing).

A backstory to the green burial option is why cemeteries didn’t welcome interring a corpse in a natural state. Without a robust casket or vault, the soil above would collapse and make it difficult to mow.

So much for thoughtful treatment of the deceased.

Beattie and Weston are irreverent mavericks in what has traditionally been a staid, slow-to-adapt industry. There are others now, including grey-haired funeral directors who work with the bereaved to arrange just what a grieving family wants – even if it isn’t an elaborate service with an open, fancy coffin.

“I believe direct-to-consumer aquamation and green burial are the future,” says Beattie.

As for planned exits, a close member of his family was a FEN client, and he is a staunch supporter. Beattie and Weston are fully on board with FEN’s work and mission.



Anne Weston

More Good Endings

Book Review by Ann Mandelstamm



– Persis Oberreither –

Pinky~Swear: Honoring My Daughter's Right to Die (2010)

Those of us who espouse death with dignity usually concern ourselves with older adults who have no hope of recovery: those with terminal cancer, ALS, Alzheimer's or other diseases for which no cure is known. We tend to forget that young people also face these terrible and tragic conditions.

In her book, *Pinky~Swear*, Persis Oberreither has written beautifully and poignantly of her 18-year-old daughter Amy's auto accident on the night of Sept. 25, 2001. It explores the heartbreaking medical and ethical challenges faced by Amy, her doctor, and her parents during the three weeks that followed the accident.

Amazingly enough, young Amy Oberreither had a living will in place, largely because of her experience with a much beloved grandmother who had steadily declined, mentally and physically, from Parkinson's.

After seeing her once vibrant grandmother reduced to helplessness, Amy urged her mother, "Promise me you'll never make me live like that." The book title comes from their ritual linking of little fingers to make the promise official.

Oberreither recalls events in Amy's life, from childhood to age 18, which make her real to the reader. Although the focus is on the accident and its aftermath, Amy never once seems to be just a patient in a coma. Through her mother's retelling, she is funny, athletic, devoted to her dog, Fudge, both affectionate and at times sarcastic – in every way a living presence.

The photographs are stunning. I couldn't help loving her.

No parent can read *Pinky~Swear* without a pounding heart. Though the outcome is known from the subtitle, I couldn't put down this gripping account. But what I liked best is Oberreither's courageous

Amy urged her mother, "Promise me you'll never make me live like that."
The book title comes from their ritual linking of little fingers to make the promise official.

honesty about each major happening in Amy's care.

For example, a wound care specialist visits Amy, and in an awkward attempt to be sympathetic to her mother, she remarks that she always tells her own daughters to wear their seatbelts. Oberreither recalls: "My eyes narrowed. Gee I never thought of that! I guess they always listen to you. I guess that makes you mother of the year."

It is exactly this kind of emotional candor that takes the reader right into Amy's hospital room to endure the long days and nights with her parents.

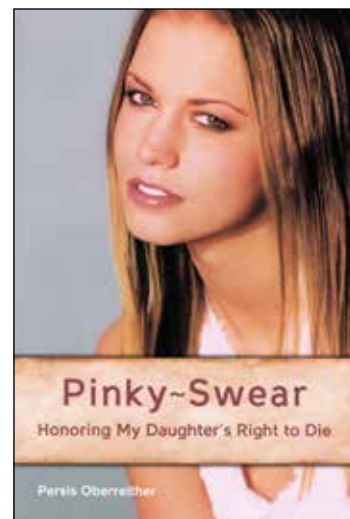
The journey they take, each decision and event in sequence, leads to the eventual awareness that Amy will probably never be off life support. While no doctor can predict exactly what will happen, and while her mother hopes that every grimace or twitch means she is waking up, Amy's coma remains deep and persistent. Her brain injury is "as bad as it gets."

Even in the midst of such tragedy, protocols must be followed. Amy's neurosurgeon, other specialists, the head of intensive care, and a Jesuit trained in bioethics (this is a Catholic hospital) talk to Amy's parents. Most people in the hospital are kind and sensitive, but not all. The committee and the Oberreithers unanimously agree that it is in Amy's best interest to have her life support removed.

Pinky~Swear illustrates a love ferocious in its intensity – and courage that never falters. But at its core is respect: respect for a daughter's deepest wishes and her integrity.

Written by a mother devastated by grief, about a talented and delightful daughter, and dedicated to the grandmother who inspired the initial discussion about quality of life, *Pinky~Swear* is an unforgettable and influential book.

Copies are available from Persis Oberreither at persisoberreither@gmail.com, or through *Living With Loss Magazine* (online).





Foreign films take spotlight

By Jim Van Buskirk, Chief FEN Reviewer

Two recent international films deal differently with hastened deaths.

Everything Went Fine (“Tout s’est bien passé”) premiered in 2021. Renowned French director François Ozon offers a powerful family drama in which the *paterfamilias*, sick and half-paralyzed after a stroke, asks his two daughters for support to end his life.

Based on the 2013 memoir by Ozon’s late collaborator, Emmanuèle Bernheim, the film follows the sisters’ relationship with their father, Parisian



Jewish art collector André Bernheim.

The family’s complicated emotional dynamics and the challenging legal and bureaucratic logistics to get him to Switzerland are movingly and unpretentiously rendered. (This story is also told from the perspective of physician Martin Winckler in *En*

Souvenir d’André.)

Plan 75 debuted last year. Set in a near dystopian future, this award-winning science fiction film directed by Chie Hayakawa imagines that the Japanese government’s Plan 75 program encourages older people to terminate their lives to relieve its rapidly aging population’s social and economic burdens.

The lives of three ordinary citizens intersect in this new reality as they confront the crushing callousness of a world ready to dispose of those who are no longer deemed to be valuable.

With a hauntingly deliberate pace, the film follows the characters as they begin to reckon with their own lives and what it truly means to live.

Unfortunately, the film doesn’t deal with the possibility that those who are ill and/or suffering might find Plan 75 to be a merciful release.



Give proper credit where due

By Midge Levy, Guest Contributor

I am writing to correct a statement made in FEN’s spring magazine in the article by Janet Hager, “CA group seeks to liberalize MAiD law.”

Ms. Hager refers to “the work that Compassion & Choices has done to establish MAiD in the 10 states and District of Columbia where it is available ...” I would respectfully point out that the Death with Dignity National Center (DWD) was largely responsible for the passage of these laws, except in Colorado where Compassion & Choices had a primary role.

DWD worked through ballot initiatives to help pass Death with Dignity laws in Oregon and Washington. Colorado also passed their law through the ballot initiative process.

DWD was critically involved in working through respective state legislatures to achieve passage in Vermont, California, Washington D.C., Hawaii, Maine,

New Jersey, and New Mexico. DWD President George Eighmey was instrumental in the legislative successes on death with dignity in both Vermont and California. He was assured by Senator Monning that they could not have passed their law in the latter state without his assistance.

All the above laws were modeled on the Oregon law written by Eli Stutsman, JD, a DWD board member. Political expertise was provided to each state by Dr. Peg Sandeen, the DWD executive director, and lobbyists engaged and paid for by DWD. Substantial financial support for associated expenses was also freely provided.

Compassion & Choices provided extensive reporting on the development and ultimate passage of these laws through the press, their impressive newsletters, and other media reports. They made financial contributions and were a presence in state efforts, inclusive of lobbying support.

We are grateful for the education they offer on this issue both to professional groups and the general public.



Writing his own Goodbye

TO: Final Exit Network
FROM: John S. M. Smith
RE: Personal Statement about my End of Life Choices
DATE: April 1, 2023

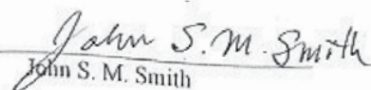
I am a retired journalist, nearly 90, diagnosed with Alzheimer's in January 2021. I have had a very good life – long, productive, healthy and with a great deal of happiness. I have served in the U.S. Army, taught journalism at UCLA and founded the country's first community TV station in Colorado and published several books.

I do not fear death. In fact, for many years I have been intrigued about what's next in the Celestial World, the mysteries of the universe and the "hereafter." I do fear the landmines ahead as Alzheimer's steals my cognitive ability. I do not want to "languish" in an expensive limbo with my cognitive ability gone while my physical body slowly diminishes. This would be unacceptable for me and for my wife and children with whom I have discussed my wishes and who support my choice in this deeply personal matter. My feelings about the limitations of aging would be very different were it not for the fact that Alzheimer's is eroding my mind while my body remains relatively strong.

I witnessed my mother's excruciating decline that left her rattling the exit door of her memory care unit, unable to escape the ravages of Alzheimer's. My sister was also compelled to starve herself to death under the care of Hospice for her advanced breast cancer. There is no comfort in these circumstances with images that continue to haunt me. My lesson is that, if possible, I must avoid such horrors for myself and out of respect for my loved ones. I have always tried to solve the problems that come my way and be prepared for the next challenge. That is what I am seeking to do with your help.

I can feel myself losing ground from week to week and sometimes from day to day. I start to do something and moments later I have no memory of what I was doing. It has become a long struggle for me to write even a short note or letter. My computer is nearly impossible for me to navigate now. Writing has always been my lifeline and it is slipping away. I find it increasingly difficult to dress myself – buttons and sleeves require help. Without caller ID, I often wouldn't know who is at the other end of a phone call. It's painful now as I struggle to remember the simplest things, people, names, events -- the very structure of my very long and very happy life. This is an agonizing process and I want to determine the end of it for myself. I am requesting that the Final Exit Network be my guide.

Sincerely,


John S. M. Smith
Date April 1, 2023

***John Strong Macauley Smith
died May 30 in Eugene, OR,
almost two months after
writing his letter to FEN
(used with permission).***

Much to consider when making The Decision

Not easy – indecision is worse

By Deborah Alecson, FEN Member

While those of us in the Final Exit Network community believe that each of us has the right to decide when and how we die, the actuality of that assertion is fraught.

To be clear, the assertion is not made from current psychological despair. It is not a solution to a crisis, but rather the expectation that physical and mental conditions will, in all probability, get worse. Or, should one be visited by certain physical or mental conditions later in life, one would rather not live. We would want to choose a peaceful way to end our life.

The contention is troublesome because it is a decision made in a culture steeped in death denial and anxiety. To choose death over life is perceived as selfish and disturbed, and to discuss the reasons for such a choice is to agitate others by triggering their death anxiety. So how do we plan for a chosen death when those we most care about struggle to understand why we can't just "suck it up?"


The death of a loved one triggers a grief response that can be the most unbearable state one can experience. The avoidance of a grief response permeates our culture. Talking about a chosen death can cause what is known as "anticipatory grief," and this is too uncomfortable for many of us.

How do we detach from this world and the people we love to summon the courage to leave? Are there conversations we should have, so those who survive do not become burdened by complicated grief? If we tell those we love of our plan, and it is received as hysterical, how will such unfinished business land after we do self-deliver?

Perhaps we can't control the reactions of others.

- How do we prepare to end our lives while also having the emotional bandwidth to be present for them?

- How do we say goodbye, forever, and choose the



*How do we detach
from this world
and the people we love
to summon the courage
to leave? ♪*

unknown: death?

Then there is our stuff and footprint in the world of the living. This may necessitate a discussion with our lawyer about who will inherit our wealth (if we are lucky enough to have any).

- What about our pets?

- How do we get help from a circle of people who do not want us to die? Or, they have cosmic beliefs such as reincarnation, and they warn that if you end your life, you will come back less evolved and must start all over!

- When do we throw things out?

- How does one maintain meaning and purpose if there is no future? How can we have a commitment to our life? Do we become more engaged – or less – with our daily lives? How do we grieve ourselves, and all the people and places that make life worth living? Or does life become about being, not meaning, and we follow our instincts like the animals we are?

It is fraught.

But not deciding is even more unsettling.



Nevada gov. vetoes MAiD bill

Dying patients and right-to-die advocates suffered a major setback June 5 when Republican Gov. Joe Lombardo vetoed a bill that would have legalized Medical Aid in Dying in Nevada.

Despite being passed in both legislative chambers – and polling that showed 82 percent of Nevadans support MAiD – Lombardo vetoed the measure while refusing to meet with its supporters. It was his 32nd veto of the current legislative session.

Though a majority of Nevada Republicans support the bill, it was sponsored exclusively by Democrats – and the bill passed in both chambers on straight party line votes.

What could possibly go wrong?

By Althea Halchuck
FEN Surrogate Consultant

A crisis is just around the corner

It was perfect Arizona weather; 70 degrees and sunny, a great day for the Model Train Collectors Association annual picnic. It's held in Scottsdale at the McCormick-Stillman Railroad Park, on 30 acres of prime land offering train rides, museums, an interactive "luxury" Pullman Presidential train car, games, and numerous model train layouts to entertain kids and adults alike.

The picnic offered every kind of expected food – hot dogs, burgers, sausages, all being grilled with delicious aromas wafting around. People (wives and girlfriends) brought delicious side dishes of potato and macaroni salads, baked beans, and deviled eggs. There were so many enticing desserts, it was hard to choose.

What could go wrong on such a gorgeous day?

My husband and I (he in his engineer's hat with the buttons proving his love for model trains) had settled down with plates of food when I looked up and saw the grill man – grey-faced, tottering, and about to pass out. His wife sat him in the shade as a few buddies offered water and a cold cloth while someone called 9-1-1.

An EMT crew arrived within five minutes. An efficient and experienced team tended to the man, took his vitals, and gave him oxygen. He was "in the pink" within minutes. *Phew!*

This could have quickly gone another way, with him in the ambulance, resuscitation paddles at the ready.

After the dust settled and the EMTs enjoyed the BBQ lunch (at everyone's insistence), I asked his wife if he was doing OK. She said he had some past heart issues, but for now, he was doing fine. She said she was his Durable Healthcare Power-of-Attorney, as they are called in Arizona. If he was incapacitated, she could make healthcare decisions on his behalf, and she knew

what he wanted, including NO CPR!

But what if she wasn't there that day? I asked the EMT boss what they would do if they needed to resuscitate him. He said they would do what they thought would be in his best interest. But they did not know him, so had no idea of his wishes or "best interest."

The grillmaster was in his late 80s, in poor health, and CPR on older adults often has a bad outcome. The force of compressions typically causes broken ribs – or, worse, brain damage.

Luckily, this day they did not have to resort to such a drastic measure. Even if it had been needed, this couple was among the very few (about 28 percent) who put their end-of-life planning in place and discuss what to do in a crisis.

In 1983, Nancy Cruzan, 25, was driving home from work when she lost control of her car and was thrown face-down into a water-filled ditch. Resuscitated, she was on life support for nearly eight years while her parents fought to disconnect her feeding tube. She had no Advance Directive or surrogate, and her crisis shined a light on the need for sound advance planning.

A medical crisis can happen at any moment, so everyone over 18 should create an emergency plan with an AD and an effective healthcare surrogate. Make a video stating your name, date, and EOL wishes. It's a backup if there are questions or conflicts about what you want when you can't speak for yourself.

Have "the conversation" about medical and EOL goals with your surrogate, family, and healthcare providers. Keep your AD updated and accessible to ensure your last wishes are honored. Don't leave final decisions to fate. (Reach Althea at 866-654-9156.)



THE BACK PAGE

A COMPENDIUM OF RIGHT-TO-DIE WORLD NEWS

Portugal

Portugal's conservative President Marcelo Rebelo de Sousa signed a bill in May to decriminalize euthanasia in the Catholic-majority country after Parliament overturned the last of his four vetoes.

Portugal became the sixth European Union country to legalize the procedure. Opinion polls have long shown the majority of Portuguese favor the right to choose medically assisted death over suffering.

Since January 2021, Parliament kept approving slightly amended versions that the president would send back to the house or to the Constitutional Court, usually citing doubts over wording. Critics said they were mere attempts to delay its introduction.

The 250-seat parliament voted 129-81 to approve the bill without changes requested by Rebelo de Sousa, effectively overturning his veto.

The law specifies that people would be allowed to request assistance in dying in cases when they are "in a situation of intense suffering, with definitive injury of extreme gravity or serious and incurable disease."

France

A new report says the introduction of euthanasia or Medical Aid in Dying (MAiD) in France would be "dangerous."

The 60-page document was produced by two French senators.

Its June 28 adoption by the Senate's social affairs committee is being seen as a warning to the government, which is expected to introduce a bill on the issue in the coming months.

The report is opposed to all forms of help-to-die options. It states that such laws would be "an inappropriate response" to patients' expectations at the end of their lives and would be "a real challenge" from a legal point of view.

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

Spain

A right-to-die group in Spain released a report in June on the first year and a half following the legalization of euthanasia. From June 2021 to December 2022, 370 people used MAiD.

The association Right to Die with Dignity lamented the difficulties faced by those who wish to seek MAiD, noting that there was a lack of commitment to it by private health providers.

Doctor Fernando Marín, one of the report's authors, said some private insurers have not responded to requests from those seeking medically assisted deaths. "There have been people waiting for a solution for six months, and they have not been told anything because of the disorganization of private health," he said.

In 2022, medically assisted dying made up 0.064 percent of all of the deaths in Spain, although the authors concede there is disparity in the data.

By contrast, the number of euthanasia deaths in the Netherlands last year was 5.1 percent of all deaths in the country. People with cancer make the most common requests for MAiD, but a growing number of people with dementia are also being helped, with 288 cases in 2022.

Australia

A young South Australian woman, whose tragic story captivated thousands in her country, ended her life by using the state's voluntary assisted dying law on June 21.

Lily Thai, 23, was terminally ill and lived in excruciating pain, but "passed away peacefully" her family said in a statement.

MAiD was legalized in South Australia in January, six years after Thai was diagnosed with Ehlers Danlos Syndrome, which causes one's joints to become loose and skin fragile – putting them at risk of severe injury.

A year later, she lost her ability to walk, use her bowels, or eat and drink without becoming sick. She also discovered her organs were failing due to a rare autoimmune disease.

New Zealand

A group of doctors who perform assisted dying in New Zealand has written an open letter calling on the government to change the wording of the End of Life Choice Act 2019, which, they say, excludes Kiwis due to an arbitrary deadline.

The MDs say the current law fails the citizens it is meant to serve by requiring that they have "a terminal illness likely to end the person's life within six months."

To get the legislation through parliament, they claim, politicians were allowed to damage and weaken the text, removing the originally proposed clause requiring only "a grievous and irremediable medical condition."





*They take control
of their dying process ...*

FINAL EXIT NETWORK
PO BOX 10071
TALLAHASSEE, FL 32302

Latest FEN research examines why some take charge at EOL

By Robert R. Blake, FEN Member

The [latest FEN research study](#), published in the international, peer-reviewed journal, *Mortality*, asked the question: “In the face of irremediable health conditions that diminish one’s autonomy and ability to enjoy life, why is it that some people let Nature, God’s will, or doctors’ treatment plans determine the timing and experience of death, and others take charge of that process and hasten their own deaths?”

The answer to that question came from FEN clients who filled out research questionnaires as part of their application for guide services. Compared to their other fellow Americans, this group turned out generally to be:

- more highly educated;
- without traditionally religious views;
- less likely to believe in an afterlife;
- more likely to make moral choices based on their own values than those offered by religious principles or social norms; and
- convinced that the direction and outcome of their lives are determined by their own decisions, not by outside forces around them.

The combination of these characteristics seems to support

these people in choosing a path not commonly followed in the United States: They take control of their dying process when faced with intolerable and irremediable health circumstances.

In identifying this combination of personal characteristics and beliefs, it also forms a non-religious moral basis and argument for deciding to hasten one’s death under these circumstances – *people living by their own principles in living and in dying*.

Together, this collection of personal beliefs and characteristics led to the concept of these people having a high internal moral locus of control, instead of a high external moral locus of control – that is, embracing the opportunity to decide for themselves how they should live their lives and how they will die, rather than following outside teachings, social norms, or purported moral authorities.

Readers are encouraged to go to the FEN website (finalexitnetwork.org) and follow the link to the research article. Read it, and follow along with the questions FEN clients were asked.

See how you are like or different from those who chose to hasten their death.

