



Magazine

NEW HORIZONS

Special Feature:

**ANNUAL
REPORT
2023-2024**

Final Exit Network (FEN):

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OUR MISSION

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

OUR VISION

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

Learn More About FEN's Mission, Vision, History, and Future...

Understanding FEN: Our Mission, Impact, and Importance

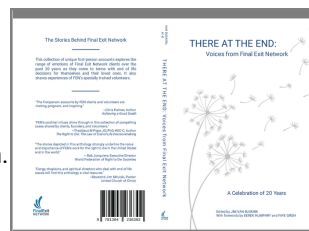
Learn more about the critical work our volunteers and staff do every day, and the impact of that work on Final Exit Network members, clients, and their families. View it on FEN's official YouTube channel: youtube.com/@finalexitnetworkofficialc-2352



THERE AT THE END: Voices from Final Exit Network

This unique anthology explores the range of experiences of FEN clients as they navigate end of life decisions. It also includes the stories of their families and FEN's specially trained volunteers, who discuss their roles as guides and, often, confidants.

See p. 13 for more information.



John's Story

This poignant, heartwarming piece chronicles John's journey following an Alzheimer's diagnosis. It is a testament to the courage it takes to face the end of life with grace and humor. Watch it on FEN's YouTube channel at youtube.com/@finalexitnetworkofficialc-2352



From the Executive Director and Board President

Dear Friends and Supporters,

As we reflect on the past year and look toward the future, it is with deep appreciation and optimism that we share the progress and future vision of our organization. This year's theme, "New Horizons," encapsulates the strides we have made and the promise of what lies ahead in our mission to educate qualified individuals in practical, peaceful ways to end their lives, offer a compassionate bedside presence, and defend each person's right to choose.



This year, we achieved significant milestones that celebrated our past twenty years and paved the way for Final Exit Network's continued success. Among our many accomplishments:

- **Program Expansion:** We launched several new initiatives that have already made a substantial impact. Our outreach programs provided critical support to more individuals and families than ever before.
- **Innovative Partnerships:** Collaborating with national and international organizations enabled us to leverage our resources and expertise, fostering innovation and working to create lasting change.
- **Enhancing Education:** We continued to develop comprehensive educational programs that provide accurate information and empathetic support, empowering individuals to make informed end of life decisions.
- **Thought Leadership:** In our last fiscal year, we celebrated opportunities to expand our presence as speakers at national and international conferences, participated in numerous podcasts, and provided articles, letters to the editor, and quotes for major publications. In addition, the publication of FEN's anthology and twentieth anniversary video series created a global opportunity for people to learn about the experiences of FEN volunteers, clients, and their families.

As we set our sights on new horizons, we remain committed to our core values of compassion, support, and dignity. The coming year will see us breaking new ground, with first of its kind dementia research and comprehensive outreach to share FEN's mission and vision.

None of this would be possible without the unwavering support of our dedicated staff, volunteers, donors, and members. Your belief in our mission and your generous contributions have been the driving force behind our success. Together, we are making a tangible difference in the lives of those we serve.

As we journey toward new horizons, we invite you to join us in this exciting endeavor. Whether through volunteering, donating, or simply spreading the word about our work, your involvement is crucial. Together, we can create a future filled with hope, opportunity, and positive change.

Thank you for your continued support and partnership. Here's to a year of new beginnings and boundless possibilities.

A handwritten signature in cursive script that reads "Brian Ruder".

Brian Ruder
Board President

A handwritten signature in cursive script that reads "Mary Ewert".

Mary Ewert
Executive Director

New Faces at FEN

Welcome to Michelle Kalapodis

BY SYLVIA LINDMAN, FEN VOLUNTEER

FEN's new executive assistant, Michelle Kalapodis, has been comfortable with the subject of death since she was 11 years old. "My grandmother was a hospice chaplain, so I grew up volunteering my time and visiting people with her," she said.



That may be one reason she is a good fit for her new job, but it isn't the only reason. Kalapodis has significant administrative experience in hospice and is a Certified Nursing Assistant. She also has field experience in hospice and home health.

"Not everyone wants to visit people in their homes, but that was my favorite part of working in the field—the genuine human connection," she said. "You learn so much with people who are facing their mortality: the power it gives to a person."

It's a plus that she lives about a mile away from Executive Director Mary Ewert, "so if I need her signature, I can drive right over," Kalapodis said. She lives in northern Illinois with her husband, Chris, a nurse experienced in intensive care and hospice, as well as their two dogs and three cats.

Kalapodis began working for FEN on July 3, following a job in hospice administration, including compliance, scheduling, and customer service. As FEN's executive assistant and fourth member of the small, but mighty, team, she welcomes the chance to help define the job. "I like puzzles and putting things together," she said. She's also detail oriented—"a little bit obsessively sometimes."

One of her tasks will be to manage FEN's presence in the ever-changing world of social media. That means keeping up with technology. "Luckily, I have an extended family, so when there are big changes I have younger cousins to explain them to me," she said.

Kalapodis loves learning. She has studied at two community colleges and is currently taking classes to earn qualifications for providing peer support in mental health.

After her grandmother died, Kalapodis did research and wrote papers on the death with dignity movement for college social studies classes.

As a key member of FEN's small staff, Kalapodis hopes her work will "make it easier for people who are pulling a lot of weight." And she hopes to help expand awareness about FEN.

"I would like to focus on outreach, especially to younger individuals," she said. "One of the things I've learned from the hospital and hospice where I've worked is that unexpected things happen. You may think it's far off, but you never know. I think people should be talking about these issues. Knowing how death can unfold brings power back to the individual decision."

Your Point of View

We'd like to hear what **you** think!



Do you have thoughts, opinions, or feedback on our recent articles? We invite you to share your perspective! Send us your letters to the editor, and your voice could be featured in an upcoming issue.

Whether it's a response to a specific story or a general comment, we value your input and look forward to reading your letters.

Email info@finalexitnetwork.org to become part of the conversation!

An Interview with Chris Palmer

BY BERNARD O'BRIEN, FEN VOLUNTEER

*Chris Palmer, FEN's newest board member, is an accomplished author, wildlife filmmaker, conservationist, and retired professor of film studies. He now devotes a significant amount of time to end of life advocacy, with his most recent book titled *Achieving a Good Death: A Practical Guide to the End of Life*, to be published in October of 2024.*

Bernard: Chris, I understand your motivation for engaging in end of life issues stems partly from having witnessed great suffering endured during the dying process of several of your loved ones.

CHRIS: Yes, I watched my parents and three brothers all die deaths involving significant and unnecessary pain and suffering. My mother languished in a nursing home for years in a quite degraded condition, and my father died of painful prostate cancer. My three brothers all died in intense pain from heart disease.

We clearly need a better and more humane approach to helping people achieve good deaths. Dying is not the worst thing that can happen to us. The worst thing is dying badly and having that suffering be needless and preventable.

B: You have demonstrated great commitment to end of life advocacy through work as a hospice volunteer and by founding an aging, death, and dying group. What drew you to wanting to take a leadership role within FEN?



C: I strongly believe in FEN's mission and vision and appreciate the fact that it is dedicated to educating the public on options and choices at the end of life, and that FEN's metric for success is not the number of exits but the number of people they have educated and helped in a meaningful way.

B: Chris, given your years of experience as a wildlife filmmaker, I assume you have borne witness to the grisly fate generally suffered by nonhuman animals in the wild at the end of their lives. Would you agree that we humans are in contrast fortunate that we can take numerous steps to manage our inevitable dying process?

C: Yes, there are many strategies we can deploy which animals in the wild obviously cannot. These include completing advance directives, having hard conversations with our loved ones about how we want to die, selecting a healthcare agent, opting for hospice rather than consenting to unwanted medical treatments, and learning about various exit strategies available to us.

Thanks to organizations like FEN, humans are not destined to suffer needlessly if we take proactive steps to bring about as peaceful a death as possible.

For more on Chris, please visit www.ChrisPalmerOnline.com.

2024-25 PROGRAM GOALS

What's Next for FEN

Strategically expand staffing to ensure leadership continuity.

As programs and resources continue to expand, it is critical that FEN ensure the long-term sustainability and resilience of our organization. Identifying and developing future leaders will maintain the continuity of our mission and values, even in times of transition. A robust succession plan not only prepares us for the inevitable changes in leadership but also strengthens our organizational capacity, fosters talent retention, and enhances our ability to adapt to new challenges. This proactive approach ensures that we remain committed to our mission and continue to serve the right to die community effectively.

Forge deeper collaborations with right to die organizations.

As FEN continues to grow and develop, the organization will seek to collaborate with other national and international right to die organizations to best serve our members and clients. Information on these programs can be found on our website at www.finalexitnetwork.org/partners.

Amplify FEN's thought leadership expertise.

As the only right to die organization of its kind in the United States, FEN recognizes the unique opportunity to utilize our network of experts to share our mission and vision. This year, FEN will seek to expand our presence as speakers-of-note at national and international conferences, seek opportunities for TED Talks and digital outreach, and continue to provide letters to the editor and op-eds for major publications and news outlets.

Augment and diversify Final Exit Network's financial vitality.

Diversifying revenue streams, strengthening donor relationships, and optimizing financial management practices will enable FEN to be more resilient and adaptable. This focus on financial vitality allows us to invest in innovative programs, respond to emerging needs, and secure the long-term viability of our mission. By prioritizing financial health, we are ensuring that our organization can continue to thrive and serve our community with excellence.

All goals ultimately support FEN's core objective: to educate about and support end of life choices. It's why we exist and why we attract dedicated supporters.

Transparency: FEN as Financial Stewards

BY JANIS LANDIS, PAST PRESIDENT



We're penny pinchers. And proud of it! Every donation we receive is a reflection of your trust in us. And we do our best to make those donations stretch as far as possible.

This is especially important to us because FEN never charges for our programs or services. We rely on donations and grants to fund our core mission.

What other ways do we save on costs?

- The majority of the FEN team are volunteers, and our few paid staff share our commitment to keeping overhead costs low.
- We don't have an office. We all work out of our homes. I'm writing this article in New York and will be emailing it to our director in Chicago. Its entire journey will be in cyberspace until ultimately it's printed.
- We only have one in-person meeting a year, in Chicago. This is a central location with reasonable flight costs. A free shuttle gets us to our airport hotel, and pre-planning enables us to keep the board meeting and the guide meeting focused.
- Many of us donate our travel expenses, in whole or in part, in lieu of reimbursement. In the past year, nearly \$8,000 in reimbursable expenses was donated by volunteers—no small amount.
- We don't have an "office supply cabinet" to raid for paper and pens. We use our own supplies, phones, computers, and printers.

And we're happy to do it. We know that your donations and membership dues are a sacrifice. Being respectful of your support is our way of honoring that.

Because of this support and our low overhead, we've added new programs over the years, including free doula training, surrogate advice, a dementia supplemental directive, and partnerships with other RTD organizations.

And we're dollar stretchers...



FEN knows the uniqueness of our mission and the importance of educating the public on end of life options. In the past two years, we have developed robust fundraising and communications programs to assist with this effort. Some highlights include:

- Our **Speakers Bureau** is going virtual more often to

increase outreach and reduce travel costs for our volunteer speakers.

- Our free monthly **Chosen Death Forums**, conducted on Zoom and moderated by volunteers, provide a safe place for our members to talk about death and dying.
- **Communications:** We developed more consistent outreach, using both digital and print to ensure we reach everyone.
- **Fundraising:** Through semiannual fundraising appeals, we spent \$21,000 and raised over \$91,000 in donations, which marks a 331% return on investment.
- **Grants:** We began a concerted effort to reach organizations that award grants in fields related to our mission. As a result of this initiative, FEN received nearly \$50,000 in grant money in the past year.
- **Infinity Society:** In addition to the more than \$665,000 left to FEN via bequests in the past year, ten individuals joined the Infinity Society, marking their commitment to remember FEN in their estate plans.

When we look at the impact of our investment in our 2023-2024 efforts, we are pleased with the results:

- Fundraising and communications costs: \$95,000
- Individual donations totaled: \$344,000

This reflects a 260% return on this investment of resources. When grants and bequests received are factored into this figure, the ROI jumps to 1,014%. Bequests and grants are incredibly helpful, but they aren't dependable sources of income. For that we rely on the unflinching support of our members through member dues.

But every coin has two sides...



No matter how we pinch our pennies and stretch our dollars, inflation takes its toll. For example, our most important expense, Exit Guide travel, is completely dependent on travel costs.

The right to die movement is also increasingly on the radar of prosecutors in many states. FEN provides free legal counsel for any guide involved in such litigation. These cases are unpredictable and require fund availability.

We have been fortunate to maintain the same dues structure since FEN began, and our board reviews it annually to make sure it is sustainable. We're pleased that, with your generosity and careful fiscal management, we are in the black!

Final Exit Network Results:



NEW PROJECTS	DETAILS	OUTCOMES
<p>20th Anniversary Celebrations</p>	<p>Held a year-long, multifaceted celebration of the 20th anniversary of Final Exit Network's founding.</p>	<ul style="list-style-type: none"> Published an anthology that celebrates the people behind FEN's critical mission. Distributed and sold the book globally. (See page 13). Created a two-video series that highlights what FEN does and how it impacts volunteers, clients, and their families.
<p>Dementia Research Study</p>	<p>FEN committed to a multiyear project to research trends and attitudes about hastening death when faced with a dementia diagnosis.</p>	<ul style="list-style-type: none"> FEN began working with Dr. Dena Davis, Dr. Katharine Stewart, and Christine Wade, MPH, as the lead researchers for the project. FEN secured a generous grant from the Donner Foundation to help support the research.
<p>Volunteer Training</p>	<p>FEN's Exit Guide program held extensive training for new volunteers. The onboarding process takes several years to complete.</p>	<ul style="list-style-type: none"> Twenty trainees successfully completed a two-day, in-person training session this spring. Other components of the training include pre-reading, virtual training, session with FEN's attorney, an integration process, and mentoring.
<p>2024 Program Goals</p>	<p>FEN set ambitious goals in 2024 around four specific initiatives: collaborations; recognition as thought leadership experts; comprehensive communication strategy; staffing resources.</p>	<ul style="list-style-type: none"> All goals were met or exceeded! Read more on the adjoining page.

2023-24 At a Glance

How Did FEN Stack Up To Its Goals This Past Year?



Forge deeper collaborations with right to die organizations.

- FEN is currently working with nine right to die organizations.
- New and renewed collaborations with Swiss right to die organizations provide FEN members with alternatives when exploring their options for a death with dignity.
- FEN's Swiss Option Advisor (and team) is developing communications to address common questions about the Swiss option.



Elevate the standing of FEN's thought leadership experts.

- A prominent article in an international newspaper (*Kathimerini* in Athens, Greece) featured FEN's work.
- Five national and international conferences brought FEN speakers in as presenters and panelists, reaching thousands of people.
- Three podcasts featured FEN leadership, with a potential reach of over 3 million.
- The *NY Times* published pieces by FEN leadership this year and sought quotes for other articles.



Augment and diversify FEN's communications plan.

Using digital, printed, social, and mainstream media, FEN reached more people in 2023-24 than ever.

- Social media followers doubled (across Facebook, LinkedIn, X, and YouTube).
- Fundraising outreach resulted in a 35% increase in new donors.
- Publication of the FEN anthology, *There at the End*, and distribution of the new video series showed a glimpse of FEN to an entirely new audience.
- Membership increased by nearly 20%.



Expand staffing to deliver exceptional programs and services.

- Recognizing that increased staffing resources enable continued excellence in program and service provision, FEN's board approved the approach of combining paid staff with contractors and volunteers to focus on communications, fundraising, and program initiatives.
- Current staff duties, job descriptions, and titles were evaluated and adjusted to best ensure organizational excellence.

FEN's success wouldn't be possible without the support of our members, volunteers, and donors. **You** make the difference. Thank you!

FEN Around the World ...

FEN Executive Director Mary Ewert and Exit Guide Program Director Lowrey Brown traveled to Ireland in September to present at and participate in the World Federation of Right to Die Societies (WFRtDS) 2024 Conference.

The biennial conference brings right to die organizations, their members, legislators and government officials, clinicians and healthcare professionals, lawyers, and other end of life advocates together globally to discuss issues around and deepen understanding of Voluntary Assisted Dying.

Lowrey's presentation was titled "Choice in Dying Outside the Medical Model: Serving Those Without Access to MAID or VSED." In particular, Lowrey compared the diagnoses of those who qualify for Oregon's MAID law with those who qualify for FEN's guide support.



L-R: Mary, Silvan Luley (Dignitas), Lowrey, Jane Morris (President, Dwd Victoria, Australia), Peter Warren (incoming Executive Director, WFRtDS), Sean Davison (Founder, DignitySA).

Mary's presentation, "Moral Locus of Control in Hastened Death When Faced with Irremediable Health Conditions," focused on past FEN research and shared the findings, trends, and attitudes as published in *Mortality* magazine.

Mary also represented FEN at the World Federation business meeting held during the conference.



Photos L-R : 1) Mary presenting to the full conference; 2) Representatives from EOL Ireland discussing efforts to pass RTD legislation in Ireland; 3) Mary, Faye Girsh, and Lowrey took a break from the conference activities to smile for the camera.



... and In Your Neighborhood

FEN offers a variety of events throughout the year, both virtually and in person. While some are available to members only, many are open to all. Check out <https://finalexitnetwork.org/events> for a calendar of events that may interest you.

Coming up:

- Monthly Chosen Death Forum discussions (members only)
- Multiple educational workshops held across the country (members only)
- Book-launch party at the San Francisco Public Library Oct 22—open to all
- Virtual book-launch party Oct 23—open to all

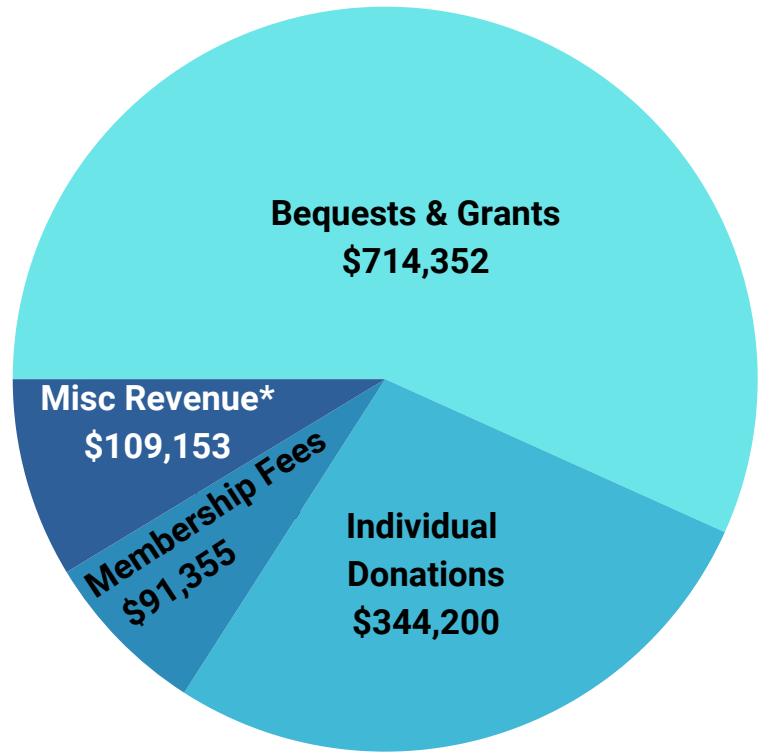
For more information, visit finalexitnetwork.org/events.

Financials: July 2023–June 2024

Highlights:

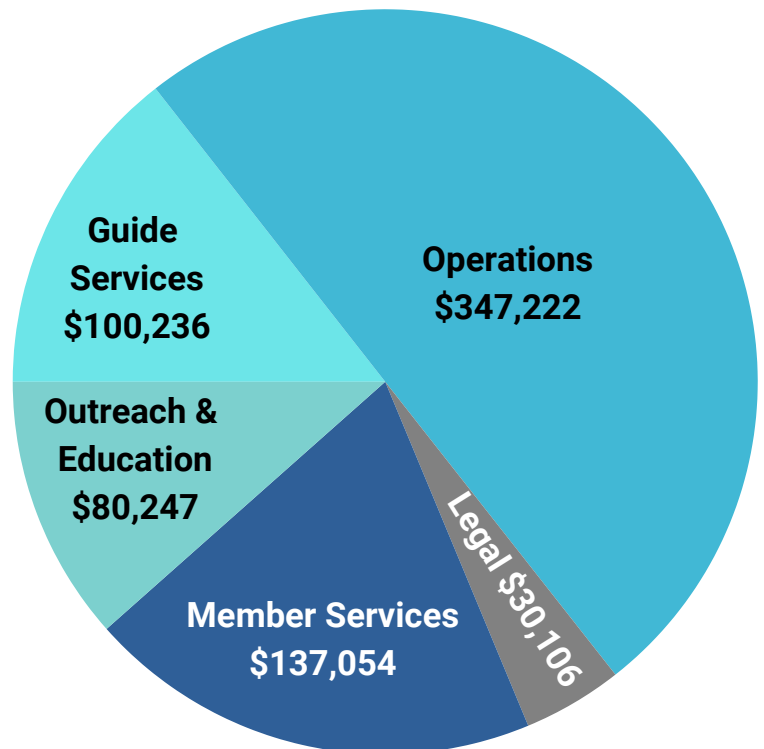
- 1,116 donors gave a total of \$1,058,552 between July 1, 2023 and June 30, 2024.
- FEN achieved Platinum Level status (the highest level charities can attain) from Candid/GuideStar, recognizing FEN’s commitment to financial transparency.
- Charity Navigator rated Final Exit Network as a 4-Star charity—its highest rating—recognizing its commitment to accountability and finance, culture and community, and leadership and adaptability.
- 71% of FEN’s expenses are directly attributed to education and program services, which exceeds best practice standards.
- FEN’s Investment Account totaled \$5,482,151 as of June 30, 2024, an increase of over \$1 million from the prior twelve months. These funds, raised through individual gifts, bequests, and grants, support all of FEN’s programs.

TOTAL REVENUE \$1,259,060*



*Does not include unrealized gain (change in the market value of held investments) of \$551,524

TOTAL EXPENSES: \$694,865



Please note that we are in the midst of our annual audit/review, so all numbers have been confirmed but are unaudited.

Volunteer Spotlight

The Importance of Speaking Up

BY SYLVIA LINDMAN, FEN VOLUNTEER



"If everyone advocated for themselves, it would become a movement," Eleanor Aronstein said. "A good death is a reasonable objective in a humane society."

In "Why I work for Final Exit," published in FEN's new book, *There at the End*, Aronstein describes how her conviction was

shaped by two deaths, twenty years apart. Her mother died of cancer in 1972. "She died over a period of eleven months, and I didn't have the vocabulary to talk about it," Aronstein said.

"When she died, I don't think she weighed 65 pounds. I was consumed with guilt and horror at the medical system that let people go to their death like this."

The guilt still lingered when, in 1991, her beloved dog ("She was like my fourth child") had to be euthanized. "She died peacefully in my arms, and I had this incredible epiphany—this is the way people should be able to die."

Thus began three decades of advocacy—and counting. Aronstein started by educating herself on the death with dignity movement. She joined Compassion & Choices. She wrote letters to the editor.

When she moved to Schenectady, New York, in 2013, she met three members of Final Exit Network who changed her life: Hedi McKinley, Martha Schroeder, and Nicole Sharp. They brought "piles of FEN literature," and they told her, "It's up to you now."

She rose to the challenge. Having taught in high school and college, she wasn't afraid of public speaking, and she knew how to be animated and engaging. She called the local

library, set a date for a program, and created a presentation. One hundred people—more than expected—showed up. "My first question, my hook, was how many of you here expect to leave this earth alive? How do you want to go? Do you want to be tethered to machines or in control? It wakes people up."

The local paper wrote an article, and word spread. Aronstein has given many presentations since then, with her husband, Jesse, providing technical and moral support. Now 86 and recovering from a broken hip, she has slowed down but is still willing to "go anywhere within a reasonable distance" if a request comes in.

"My first question, my hook, was how many of you here expect to leave this earth alive? How do you want to go? Do you want to be tethered to machines or in control? It wakes people up."

Raised Catholic, Aronstein acknowledges that overcoming guilt is a big hurdle for many people to accept any form of self-deliverance—including many in state legislatures. She advocates for a Medical Aid in Dying law in New York that has been stuck "in committee" at the state legislature for eight years.

Modest about her advocacy for FEN, she said, "I don't do the moving and the shaking." But she is always thinking about the cause. The publication of *There at the End* prompted Aronstein to muse that maybe her local independent bookstore might be interested in hosting a program. "That would get us an article in the newspaper," she said. And so the word spreads.

Did You Know? 73 dedicated volunteers are at the heart of all that FEN accomplishes. Some of the roles that volunteers perform include:

- Exit Guides
- Regional Coordinators
- Interviewers
- Speakers Bureau members
- Authors and editors
- Medical Review Committee members
- Board members
- Facilitators



Thank you to this amazing network of caring, trained volunteers who support mentally competent adults as they navigate their end of life journey.



New Nevada Law Redefines Medical Care

BY PAMELA BANKERT, FEN ATTORNEY

All medical directives written-when-competent remain in force and must be adhered to, even if the patient becomes incapable of asserting the directive because of dementia. The healthcare representative (HCR) can require adherence to the advance directive (AD) on behalf of the patient.

However, “comfort care,” such as hand feeding (as opposed to a feeding tube or IV), is not medical, and nursing homes may continue to provide this despite an AD stipulating that no food or hydration be provided.

Our FEN attorney, Pamela Bankert, explains a new law in Nevada that allows feeding and hydration to be treated as medical care.

*In 2019 the Nevada legislature took some extra steps in the expansion of power of attorney (POA) rights in end of life situations. In certain situations, where a patient is over the age of 18, **and** has executed a declaration, **and** has a terminal condition, the healthcare representative (HCR) can give consent to withhold “comfort care” if such care serves only to prolong the process of dying.*

The concept of “life sustaining treatment” as applied here is defined as treatment “which serves only to prolong the process of dying.” As we know, antibiotics, hydration, nutrition, and feeding, as well as other interventions, can and do prolong the process of dying. As medical interventions, they remain enforceable by the HCR on behalf of a dementia patient.

In Nevada, a duly appointed HCR now can elect to decline “comfort care” on behalf of a patient. A “terminal condition” is defined as “an irreversible condition which cannot be cured or modified by any known current medical therapy or treatment, and which, without the administration of life sustaining treatment, will in the opinion of the attending physician result in death within a relatively short time period.” Although the criteria are narrow, they apply to many patients. We believe it can apply to a dementia patient in the end stages of the illness.

This means that a person, while competent, can elect Voluntary Stopping of Eating and Drinking (VSED) and have it enforced by their HCR should they become incapable of articulating that request for themselves.

Why does this matter? A dementia patient may have no sense of hunger or thirst. But when a caretaker puts a spoonful of ice cream in front of them, they will reflexively open their mouth and eat. The same is true for a beverage presented with a straw.

Thus, in Nevada, and only in Nevada, an HCR can implement VSED on behalf of their patient and require that caretakers honor this. Because a person in the late stages of dementia is often in the process of shutting down their body, the withdrawal of food and water is not painful. On the contrary, by withholding nutrition, we are allowing the merciful ending intended by our bodies instead of prolonging a life by thwarting this natural dying process.

The statute itself provides legal protection for HCRs as well as medical and healthcare personnel who follow the statutory language. So far, we haven’t seen any legal challenges to this specific statute in Nevada.

We are hopeful that other states might recognize this option. If you don’t live in Nevada, perhaps using the Nevada form or inserting your own request for refusing this type of “comfort care” might be useful. We welcome test cases of this advance directive that use either approach. If you are aware of any instance in which a facility denies this request, please contact us at info@finalexitnetwork.org so we can consider litigating the issue.

In response to the numerous questions posed by FEN members, we are pleased to provide this new Legal Corner magazine series. If you have topics you’d like to see addressed, please email us at info@finalexitnetwork.org.

In His Own Words

In response to our recent request to “Tell Your Story,” we are pleased to share this piece, written by FEN member Wally Klatch. Wally earned his master’s degree from Purdue University and was a management consultant and operations manager at multinational corporations. While he has lived in both the US and Israel, he currently lives in Denver. Wally was diagnosed with mild cognitive impairment and has been interviewed on Israeli television several times about his journey with early-stage dementia. He is active in several organizations that focus on this condition and has agreed to share his journey in this magazine. This installation is his first, but he also chronicles his experience in his blog www.mciandmee.com

BY WALLY KLATCH, FEN MEMBER

Being 70 years old is for old people. Being diagnosed with early-stage dementia is for brain-falling-apart people. Needing help in living my life is for un-functioning people. None of these had anything to do with me.

None of them had anything to do with me until that day in October 2022 when the neurologist looked at the test results and told me that I have early-stage dementia. I thought that’s the worst news I would get, and it was, until January 2024 when the neurologist told me I also have Parkinson’s disease (PD). PD has a bigger effect on my day-to-day life. I had figured out how to deal with forgetting so much because of the dementia, but with the PD I physically couldn’t function as I had. I lost the practical use of my left hand in many ways—manual effort became a fingers-of-the-right-hand activity, and I didn’t dare pick things up since they would drop because of the shaking. Large physical limitations were added to the mental limitations, and the future looked very bleak from there.

What happened next couldn’t have happened without having first gone through these things. What happened was at first tiny and was completely overwhelmed by the terrible limitations that had come into my life, and it was just a feeling. It was a tiny feeling that oh so slowly started to take place in my life. And that’s exactly what it was—feeling. As the brain-driven life I had lived up to then was reduced—as I went through mild cognitive impairment (MCI) to use the common phrase—there was room opened for something else besides the cognitive. That “something else” was feeling, and in a way I had never experienced before. The more I paid attention to it, the more it was there, and the more I felt happy that it was there. I looked around and couldn’t find this described anywhere so I made up a name for it, mild

emotional enhancement (MEE), and created a web page describing it particularly as related to MCI. That site is mciandmee.com. And the flow continued. I kept hearing about mindfulness, and I felt something was missing there, too, so I created www.Feelingfulness.com to go with it.



Let’s put words like these in our language and start feeling them and using them, and who knows where it will lead! And I know where dementia leads, and as I’m on my way there I want this approach to be available to me, so I invented I-Have-Now.com, which says that my life and my death are part of each other as the dementia advances. And for me expressing it, even on a T-shirt (see photo above), is part of feeling it.

I feel that a word that expresses what I’m going through is “release” and that it’s important to me to explore this more. Actually, now that I realize that I’m on my way to the final exit, I feel that there is very much to explore here—I’ve been on the way since the moment I was born and didn’t realize it at all. We’re all here, and the world feels completely different when we realize that fact.

Let’s explore it together—I’ll tell you what I feel along the way on my journey, and I welcome your feelings as you are on yours.

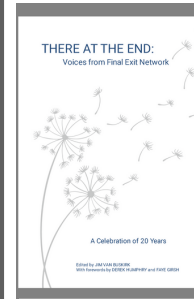
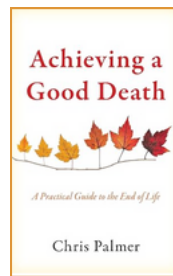
Death and Dying in the Media



- Christopher Palmer-

Achieving a Good Death: A Practical Guide to the End of Life (October 2024)

This accessible, thoughtful, and thorough guide is an excellent introduction to the complexity of end of life issues. It covers a wide range of topics, including death cleaning, ethical wills, palliative care, hospice, end of life doulas, options for disposition of bodies, how to deal with grief, and more. Of particular relevance to FEN members is chapter 8: "End of Life Options," which states that "an intentional death gives the dying person peace of mind, a sense of agency, the chance to die at home, the end of unnecessary pain and suffering, and reduced trauma for loved ones." Seemingly straightforward, this chapter is remarkable for the fact that this information is rarely included in "comprehensive" resources about end of life issues. Palmer painstakingly disambiguates between medical aid in dying, euthanasia, and suicide, and even includes a page accurately describing FEN's support services. The appendices include Palmer's personal letters describing end of life wishes to physicians and family members, ethical wills, and even a eulogy. "A Letter to My Family About Ending My Life" might serve as a possible template for readers, while the notes offer a veritable bibliography of further useful titles. At nearly 300 pages, this well-written and well-researched resource offers a wealth of information for its readers.



Get Your Copy Today!

Publication of the FEN anthology, *There at the End, Voices from Final Exit Network*, resulted in nearly 1,000 books distributed in the first month.

See what readers have to say:

- "FEN's cardinal virtues shine through in this collection of compelling cases shared by clients, founders, and volunteers." ~T. Pope, JD, PhD, HEC-C, Author of *The Right to Die: The Law of End-of-Life Decision Making*
- "This book is perfect. With personal stories it describes the beauty of and need for Final Exit Network's work. They provide compassion and education on how to avoid...well...a fate worse than death. They are true heroes. And it's a lovely book to read!" ~C. Phillips



Copies are available (\$15 for book, \$5 for ebook) via the link at www.finalexitnetwork.org

A proud disclosure: Chris Palmer joined the FEN board in June 2024 (see p.3).

-Documentary by Cathy Henkel and Sam Lara- *Laura's Choice* (2021)

Laura ("no shrinking violet!") Henkel is a delightful protagonist in this humorous, heartfelt, and life-affirming documentary. Savvy about the power of film, she enlists filmmaker family members—her daughter, Cathy, and her granddaughter, Sam—for her call-to-action to promote discussion of end of life options. When, at 87, Laura starts a precipitous decline after an accident on a long-awaited European trip with Sam, she insists on hastening her own death. At first Cathy and Sam think it's "weird and confusing," but soon accept Laura's determination. Laura quickly transforms herself into an activist, writing a manifesto, launching an online forum, and campaigning to help change Australia's laws. "It is a cause for which I am prepared to die," she quips, noting repeatedly that while not ill, just in increasing declining health, she should have the right to self-determination. Interspersed are conversations with right to die advocates and opponents, a Mad Hatter's tea party farewell gathering, the filmmakers' complicated emotional responses to their assigned task, and Laura's final breath at the Pegasos clinic in Switzerland. Chris Haws—psychologist, certified grief counselor, and the film's executive producer—discussed the film in his March 10, 2024, post on *The Good Death Society* blog. To watch this feisty nonagenarian's fitting legacy, visit lauraschoice.org.



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