VOL 24 • NO 1 • WINTER 2025

Final Exit Network Magazine

Exploring Choice in Dying

Final Exit Network (FEN)

IN THIS ISSUE

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.

UPCOMING EVENTS

- **January 27: Seeing Death Clearly Podcast**: Podcast host Jill McClennan will interview FEN's Brian Ruder and Lowrey Brown. Listen at www.endoflifeclarity.com/seeing-death-clearly-podcast

- **Chosen Death Forum**: Monthly online discussion group for FEN members facilitated by trained FEN volunteers. More information: finalexitnetwork.org/services/chosen-death-forum

Check out FEN's events calendar for upcoming End of Life workshops and other events online and in your region: finalexitnetwork.org/events

Folks recently gathered in Raleigh, NC, to attend the FEN workshop "Are You Ready," presented by FEN Exit Guide Mary Ellen B.

From the Executive Director


Anthology editor Jim Van Buskirk and FEN volunteer Jenne M. co-hosted a book launch event in San Francisco on October 22.

FEN representatives were guests on the "Comforting Closures" podcast several times this fall.


Faye Girsh, Sean Davison, Asunción Alvarez, and Stefanie Green at the WFRtDS conference in Ireland.

Dear Readers,

It is with profound respect and gratitude that I write this message each time we publish the Final Exit Network magazine. As we reflect on this issue's theme of choice in dying, we delve into the core of FEN's mission: to ensure every individual has the autonomy, dignity, and compassion they deserve at the end of life.

Choice in dying is not merely a matter of practicality—it is an assertion of human rights and personal agency. It recognizes the diverse paths we each take in life and honors the individual decisions that define our last chapter. Whether managing a terminal illness, navigating unbearable suffering, or facing the realities of aging, the ability to choose how and when we depart is an act of profound self-determination.

This issue explores the many dimensions of end of life choice. The articles within are a testament to the bravery and resilience of those who advocate for the right to die with dignity and those who have walked this journey with loved ones.

We know this is not an easy subject to discuss. But silence and stigma only compound the suffering of those who feel abandoned in their most vulnerable moments. By bringing these conversations into the open, we affirm our shared humanity and commitment to justice.

At Final Exit Network, we are dedicated to empowering individuals with information and support. Together, we strive for a world where everyone has the resources and freedom to make deeply personal end of life decisions aligned with their values.

Thank you for your continued support and engagement. By championing this cause, you are part of a movement that is reshaping society's understanding of autonomy and compassion at the end of life.

With determination and hope,

Mary Ewert
Executive Director

From the Board President

Dear Readers,

As we enter 2025, several people have asked how the new administration and its policies might affect FEN and its services. Will we have to make any changes to our current services? Will we eliminate some states that we currently serve, like West Virginia, which just passed a constitutional amendment to ensure they will not have medical aid in dying laws?

First, we will not panic. We will continue to provide our services in all states. The need for our services will not change because a new administration is in charge. In fact, the need may be more important with the possibility of cuts in social services like Medicare and Medicaid. Our population is aging, and the price of care is rising. One out of three people over 85 has some level of dementia, and the cost of memory care can be more than $10,000 per month, which few Americans can afford. And it is important to remember that the work of caregiving falls disproportionately on women. More importantly, for individuals who do not want to live in a demented condition, it is galling to think of the inheritance they had hoped to leave their family drained by for-profit facilities that keep them alive against their wishes. People need reasonable, affordable, and comfortable choices for managing their end days.

Second, I want to remind everyone that what FEN does is legal, safe, and peaceful. It is legal for a person to hasten their death and for their family to know they are going to do it. It is not legal to provide the means or physical assistance, neither of which FEN guides do. Our guides are trained to follow the policies and procedures outlined in the guide program handbook, which is reviewed annually by our board. We provide information that allows people a choice in how and when they die. West Virginians can deny themselves the right to medical aid in dying—though why they would deny themselves a basic civil liberty is a mystery to us—but the First Amendment to the US Constitution protects Final Exit Network's right to speak and educate our clients and the public.

We will continue to be diligent and thorough in our application and guide processes. We will make sure that clients know their safe and legal options, including medical aid in dying laws, going to Switzerland, and voluntarily stopping eating and drinking. We will make sure that clients are having those difficult conversations with their close loved ones. And we will continue to value both personal autonomy and the social fabric of relationships, while protecting our organization for the long term.

Finally, we will spend more time on podcasts, at conferences, and in association meetings educating people on the legality and importance of choice in dying. People should understand their options, regardless of what they finally choose to do. Most people today will let nature—or, more accurately, the medical system—take its course, and die in a hospital or in their residence with hospice care. But some of us will choose to die on our own terms. Final Exit Network will be there for those people who make that choice and qualify for our services.

Sincerely,

Brian Ruder

Brian Ruder
President, FEN Board of Directors

You Ask. We Answer.

Q: Can FEN lobby for legal change? If so, why doesn't the organization do so?

Occasionally, we receive inquiries about whether Final Exit Network will support legislative actions–for example, by signing on to a letter of support for a particular bill related to medical aid in dying (MAID). We decline such requests. You may ask, why? It's a good question, with a multipart answer.

First, we look to FEN's mission, the unique role we play in the broader aid in dying movement, and why our work is so important. *We are here for suffering and dying people* ***today***–for the many people who don't live in states with MAID laws, who don't qualify, who can't access the law, or who simply prefer to use FEN's Exit Guide Program. Simply put, legislative work is not our mission. We serve, and by our service we advocate–not for any specific legislation, but for a basic human right.

As our Articles of Incorporation state: FEN "is organized and shall be at all times operated exclusively for charitable and educational uses and purposes … including but not limited to public education with respect to aging and the terminal condition and the provision of counsel and support to terminally ill individuals."

Second, we take our legal and tax status into account when considering advocacy. FEN is organized as a nonprofit corporation with federal 501(c)(3) status. This means (among other things) that members' and donors' contributions are tax deductible. Organizations with 501(c)(3) status are by federal law limited to charitable and educational purposes and are prohibited from engaging in lobbying, meaning any kind of advocacy for or against a specific piece of legislation.

As with many things tax-related, the rules are complex. Although the IRS does allow for certain limited exceptions to the "no lobbying" provision, compliance with those regulations requires the attention of staff and consultants and could open FEN to challenges to our tax status. A "no lobbying" position is simpler, safer, and less costly.

This "no lobbying" stance applies to Final Exit Network, the organization, not to individuals who may be affiliated with FEN. Many volunteers, staff, donors, and members individually belong to organizations working for legislative change. As individuals, we're certainly not opposed to the passage or expansion of MAID laws, limited though they may be. But keeping FEN's mission and tax status in mind, the organization itself refrains from lobbying.

If you have topics you'd like to see addressed in a future Legal Corner, please email us at info@finalexitnetwork.org.

Creating a Legacy to Be Proud Of:

How Do You Want to Be Remembered?

BY CHRIS PALMER, FEN BOARD MEMBER

Our legacy is the imprint we leave on the world, especially on those we love and care about. When we think about the kinds of memories and values we want to pass down, we can make intentional choices that strengthen our legacy and preserve the essence of who we are for future generations.

Building a meaningful legacy is about embodying virtues, sharing life lessons, and creating memories that will live on in the lives of others.

Why Focus on Legacy?

Reflecting on how we wish to be remembered provides an opportunity to deepen our relationships and instill values that will continue to guide our loved ones after we are gone.

When a loved one dies, our actions can carry forward their spirit. By choosing to live in ways that honor their memory, we transform our pain into purpose, turning grief into a positive force that helps sustain their legacy alongside our own.

Embody the Virtues of Cherished Loved Ones

A beautiful way to keep the memory of a beloved person alive is to consciously embrace and carry forward their virtues. If they were known for kindness, you might focus on showing compassion in your own life. By living in ways that reflect their best qualities, you allow their influence to remain alive, connecting with them in spirit and purpose. This intentional living is a powerful way to transform grief into an active tribute, as your actions become a reflection of their legacy.

Write an Ethical Will or Legacy Letter

An ethical will, or legacy letter, captures the essence of who you are, preserving your values, beliefs, and hopes for future generations. This document can contain:

- Reflections on life experiences that have shaped you
- Key family history and traditions you want to pass on
- Lessons and values you believe are important
- Messages of love and advice for family members

Legacy letters allow you to continue your role as a parent, friend, or partner beyond your physical life, providing wisdom and comfort to those who read them.

Capture Your Story: Memoirs and Story Collections

Consider using services like StoryWorth to document your life stories. By answering questions about your experiences, challenges, and achievements, you can create a memoir for future generations. This compilation not only preserves memories but also helps family members understand and appreciate your life journey.

Digitally Archive Your Legacy

Creating a digital legacy can be a powerful way to preserve important family artifacts and personal reflections. Organize documents, letters, and photographs on platforms like Google Drive, making them accessible to future generations. This approach also ensures that treasured family letters, photos, and heirlooms are available in one place, clearly labeled for those who will find meaning in them.

Keep a Journal for Future Generations

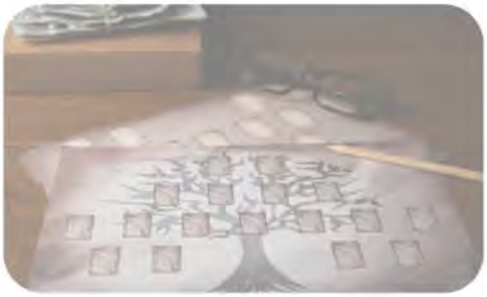
A personal journal can be an invaluable keepsake, offering insights into your daily life, thoughts, and feelings. Regular entries that reflect on significant events, family traditions, or insights from everyday life will help future generations feel connected to your personality, thoughts, and experiences. A journal is a living memory that gives others a window into your world, one they can cherish long after you're gone.

Preserve Family Recipes

Food has a powerful way of bringing people together. Compiling a collection of favorite family recipes and sharing stories associated with them is a meaningful way to keep traditions alive. A family recipe book can become a cherished heirloom, passed down and enjoyed for generations, evoking the warm memories of shared meals and the comforting aromas of the past.

Mentor and Support Future Generations

Legacy isn't just about what we leave behind; it's also about how we invest in others while we're here. Consider mentoring young people and offering guidance and encouragement to those who need it. Whether through formal mentorship programs or informal relationships, your impact on their lives can carry forward, enriching their lives and preserving the lessons you impart.



Create Family Photo Albums with Stories
Organize family photos in albums with detailed captions and stories that provide context. Explain who is in each image, where it was taken, and any meaningful details. These captions turn photographs into narratives, allowing future generations to connect with family history and understand the people in the pictures on a personal level.

Research and Document Your Family Ancestry
Researching family ancestry and creating a family history book is a beautiful way to build a lasting legacy. By documenting your family's history and sharing your ancestors' stories, you provide a deeper connection for your descendants, enriching their sense of identity and belonging.

Encourage a Memorial Tradition
One way to ensure your memory lives on is to ask loved ones to gather annually in remembrance, perhaps through a shared meal or gathering. These gatherings can serve as an opportunity to reflect on shared memories, tell stories, and pass down family traditions, keeping the spirit of connection alive.

Support a Nonprofit or Cause You Believe in
Supporting a nonprofit organization that aligns with your values is a powerful way to create an impact that lasts. By investing in causes that make a difference, you contribute to a better world that benefits others even after you are gone, leaving a significant mark on the world that reflects your values, principles, and priorities.

Final Thoughts: Shaping a Legacy of Meaning and Purpose
Your legacy is not just a collection of moments, values, and stories that extend beyond your lifetime. It's a narrative that you have the power to shape. By living intentionally and thoughtfully, you can determine how you will be remembered and cherished.

The above strategies offer a way to build a legacy of connection, support, and love. Remember, the essence of a meaningful legacy lies not only in what you do but also in the love, wisdom, and kindness you leave with those who continue your story.

FEN has been the recipient of many generous bequests through the years, each of which has contributed significantly to FEN's ability to sustain our critical work. This generosity provides the resources we need to continue our vital work and expand our outreach.

By choosing to include FEN in your estate plan, you will become a member of our newly formed Infinity Society, a group of forward-thinking supporters who have made a lasting commitment to our cause. We hope you'll give serious consideration to becoming a founding member of the Infinity Society. For more information or to join the Infinity Society, please reach out to us at info@finalexitnetwork.org or visit finalexitnetwork.org/bequest-form.

Ann Mandelstamm:

With both heavy and happy heart, we want to share that our beloved Ann Mandelstamm exited in early November. She was dedicated to choice in dying, volunteered tirelessly for many years, and mentored many FEN volunteers.

A few years ago, Ann started making bookmarks with sayings that spoke to her. Two stand out now. One of her earliest: "Find your tribe, love them hard," and her last: "I've had a nice long turn on the swing!"

We are so grateful for Ann's service, her giving spirit, her humor, and her kindness to all. Below is one of Ann's final gifts to the FEN community, her message to us.

~Mary Ewert

Why I Plan to Die in My Middle 80s

BY ANN MANDELSTAMM, FEN VOLUNTEER

For some years now I have planned to end my own life in my mid-80s, unless an accident or illness takes me before that time. This is a decision I have given much thought to, not something I arrived at without deliberation. I have no religious or ethical problems with ending my life, as long as I do it in a responsible way and with the respect and support of my family.

Why do I believe I have the right to make this choice?

I was educated in traditional religious schools, but I no longer accept or practice that faith, although I have great respect for all sincere religious practices. I would define myself basically as an existentialist, a person who believes that while people seek unity and purpose in life, life is basically both mysterious and contradictory; we have to make some choices in facing these contradictions. I have lived my life as well as I could, and I did this by making reasoned choices both for myself and for those whose care and well-being have meant so much to me: family, friends, and community. I have tried to think honestly about these things, no doubt making errors in the process, but struggling to do my best, to make my fullest effort in an imperfect world. So, to answer the question, I believe we all have the right to make choices for ourselves, as long as we do so responsibly.

Why do I think 80+ years is long enough?

By my mid-80s, I have raised my children, rejoiced in my grandchildren, tended to friends and neighbors, taught for many years, earned a living, and made contributions, however modest, to society. While I still might have some years left to continue these efforts, the odds are not in my favor that more years will necessarily add quality to my life or that of others. The odds of developing dementia increase with the years, and the chance of a bad fall, serious accident, stroke, or other circumstances are more likely. I never want to be a burden to anyone, nor do I want to be a burden to myself.

I am now 85, and although I have so far not manifested symptoms of dementia, I am becoming increasingly aware that I am starting to lose cognitive energy or agency. Things that used to be fairly easy now seem more arduous, more demanding. I find myself losing "bandwidth," especially for things that require new technology. Everything takes more

thought, more energy, more determination. In my volunteer work, I see evidence of people losing this cognitive agency. Sometimes my friends and I use the expression, "We may have to leave something on the table." We can't afford to wait too long.

Losing autonomy could make me a burden to myself and others. In addition, we have very limited resources on this planet. I want to make sure those resources go to our youngest and most deserving citizens, our children.

Mary Pipher, psychotherapist and author, explains this beautifully in an op-ed in the *New York Times*, March 6, 2020: "Like almost all of my peers, I want to die young as late as possible. I don't want to live beyond my energy level. I don't want to suffer dementia or lie helpless in a hospital. I want to die while I still believe that others love me and that I am useful." To which I say, "Exactly, dear Mary. Thank you."

Do you see yourself as an outlier, someone extraordinary, in making this decision?

Not at all. I couldn't be more ordinary. It seems a choice made with common sense, to be honest. I think my decision is not only in my best interests, but also in those of society.

The work that I have done my entire professional life reaffirms this decision for me. For over 35 years I taught English: grammar, writing, and literature. In every book, poem, and play that I read, I recognized that life is cyclical. We are born, grow to maturity, contribute to our families and communities (if we are lucky), and eventually we die, making way for future generations. Every day when I go outside to walk, I see the same cycles in nature. Spring brings new life, in animals, insects, birds, and vegetation. There is a period of flourishing, then as the year moves on to its close, things grow dormant or die, leaves fall, there is a period of barrenness, and in the spring the cycle begins anew. Just as my parents, grandparents, and great-grandparents lived and died, so will I. Hopefully we will have done our best to contribute to the world, and then it will be over for us. The next generation will have its turn.

I hope that I leave behind me plenty of love, cherished family and friends, good conversations, encouragement for others, aspirations for our country and our world, wise and lovely books read and shared, gorgeous music savored, beautiful things enjoyed immensely, and happy memories. To be candid, I have had a multitude of failures and disappointments too. Hopefully, I've learned from all of it. I am so content with my life. I couldn't wish for more.

Thanks to Ann's family for sharing the wonderful photos for this piece, including a copy of the City of Saint Louis Resolution from November 2024 honoring Ann's life (at right). It mentions Ann describing "the three most important aspects of her life as family,... teaching,... and volunteering with the Final Exit Network."

City of Saint Louis

Resolution

Dr. Richard "Dick" MacDonald:

BY FAYE GIRSH, FEN FOUNDER

How dare Dick MacDonald die? I always hoped that he would be there if I needed help. My only wish is that his death was peaceful and gentle—the way he made it for those clients who died in Hemlock's Caring Friends Program between 1998 and 2005. Dick was involved in virtually every Caring Friends case, personally attending over 85 exits in four years–more than in his 50 years in medical practice.

Dick served as the medical director for the Hemlock Society USA, an appointment made early on by its founder, Derek Humphry. In 1996, the year I became Hemlock's executive director, a groundbreaking event occurred: for the first time in history, someone died with the assistance of a doctor under a legal framework. This happened in Australia, with Dr. Philip Nitschke providing the medical aid. That same year, in the United States, the Second and Ninth Circuit Courts ruled that medical aid in dying was a constitutional right—a pivotal moment in the movement for end of life autonomy.

We felt so close to achieving our goal of providing compassionate assistance to suffering patients! However, the following year, the US Supreme Court overturned the lower court victories that attorney Kathryn Tucker had secured for Compassion in Dying. This unanimous decision dealt a significant blow to our efforts, especially after our earlier unsuccessful attempts to place a model law on the ballot in California and Washington.

In response to this setback, we in Hemlock began discussing an alternative approach. We considered guiding suffering individuals who reached out to us on how they could take matters into their own hands, inspired by the ideas in *Final Exit*, Derek Humphry's groundbreaking bestseller first published in 1991. To turn this vision into reality, we launched the Caring Friends Program, with the incredible Lois Shaffer leading the initiative and the amazing Dr. Dick MacDonald as our medical advisor.

Through this program, we discovered that we could legally share information with individuals, provided no physical assistance or means were supplied. By 1998, we trained our first class of 28 Caring Friends volunteers, who began offering support to people across the country, ensuring that those in need had access to compassionate guidance during their most difficult moments.

Dick MacDonald was a patient and thorough teacher and almost always accompanied the Caring Friends team when they went to visit a person requesting our services. In rehearsing how a meeting might go, I often portrayed the dying patient. That's when I realized what a joy it would be to have Dick at my side if I were taking my last breath. He always had a warm smile, gentle touch, and clear explanation of what was to come. Families and loved ones expressed profound gratitude for our team and for the kindness and patience of Dr. MacDonald. As one family shared, "He meant the world to me and my family and was a life saver for us when my mom needed to pass." This sentiment was common.

A native of Canada, Dick presented in both the US and Canada about the Caring Friends program. His sincerity and passion were persuasive. In 2004, a group of dedicated Hemlock volunteers, including Derek Humphry, me, Dick, some Caring Friends volunteers, and Hemlock chapter leaders, formed Final Exit Network. FEN just celebrated its 20th anniversary and continues to use the Caring Friends model, which is truly a blessing to many, and which

Remembering a FEN Pioneer

Dick made sure embraced kindness and compassion.

Dick MacDonald's legacy lives on in the countless lives he touched, reminding us all of the profound difference one person can make in bringing dignity and peace to those at the end of life.

~Faye Girsh, with love

◆

FEN Founders and Heroes

Dick played a critical part in raising early awareness of The Hemlock Society among his peers in the medical community as well as in the general public. At the international level, he was a board member of the World Federation of Right to Die Societies for 10 years, serving as its president for two years.

Dick created the model of a Caring Friend/Exit Guide, combining reassuring knowledge and calm confidence with enduring respect and compassion for anyone suffering an intolerable quality of life. With his signature moustache and flowered shirts, he also provided a healthy dose of suave playfulness, helping to balance what might otherwise have been unnecessarily dark and emotionally draining situations.

~finalexitnetwork.org/founders-and-heroes

Leading with Compassion

BY JANIS LANDIS, PAST PRESIDENT

At my very first FEN meeting, I had the immense good fortune to sit next to a very unassuming and quiet individual. His name was Dick MacDonald, and our brief conversation illuminated the path I wanted to follow.

After introducing ourselves, I asked him to tell me about his role as a physician in responding to irremediable physical suffering. He told me this story:

Dick was approached by a patient with severe multiple sclerosis. She had managed to save sufficient doses of medicine to end her life. Her only relative, a brother, was not supportive. She did not want to die alone, and she did not want to leave with bitterness between her and her brother.

Dick told her to ask her brother to live in her apartment with her for one week. He could not assist her in any way. He could only observe her life as it actually was, day in and day out. The brother agreed.

After a week, the brother recognized his refusal to support her was not an act of love, but was in fact the very opposite. He supported her decision and said that he wanted to be at her side with Dick when she drank the lethal dose.

Dick had warned her that the medicine was bitter. She took a sip, grimaced and said, "I'm going to drink this if it kills me." Realizing the irony of that comment, the three of them smiled and then burst out laughing. Dick recounted that it was with that sight and that sound that she drank the medicine and died.

I have never forgotten that story. It represents everything that made Dick so special–his understanding of psychology, the importance of love and family support, the courage to choose and to make your own path, and most of all, his greatest gift: compassion.

> ***Compassion is the wish to see others free from suffering.***
>
> **~ Dalai Lama**

In Their Own Words

Ashes in Body Form

BY WALLY KLATCH, FEN MEMBER

This is the second installment of this series, which first appeared in the Fall 2024 FEN magazine. Wally was diagnosed with mild cognitive impairment and is sharing his journey with early-stage dementia.

Yesterday I went to the funeral home to make arrangements for my cremation, to go from body to ashes. Even though I knew I would go through this process, actually doing it, being there, talking about the details, and seeing things like the display room for caskets and scattering tubes was different than just thinking about it. It left me rather shaken and with my stomach churning.

As I left for a walk this morning, I felt completely different, I was Dyliving (living with the acceptance that comes from awareness that dying is happening). I realize that I am already ashes that are still in body form. What an incredible release! I can relate to myself as having already gone through all this, and my body has to catch up. I'm already ashes and everyone else is already ashes, we're all already ashes (or dust or smoke or dirt or whatever) just still in human form! I felt exhilarated and asked someone to take my picture–my first photo as ashes still in human form.

As part of this process, I've already created and placed my tombstone on my webpage MCIJourney.com. It's read by an Israeli woman and has the Hebrew and English translations linked next to the recording. I feel that it best expresses what I would have liked to have brought into the world.

My Shattered Door

BY NICK SHERIDAN, RETIRED FEN VOLUNTEER

In the early 2000s, I started volunteering for FEN. I became the coordinator of volunteers and patients, ensuring that the volunteers stayed in touch with people who had applied to the service and submitted appropriate medical evidence, and reinforcing with them the finality of what they were planning to do. I ran training groups for new volunteers. I loved this job, in line with my moral belief that each of us has the final right to decide on our lives and also our deaths. I became a virtual companion for people with incurable conditions who had not decided when to die, or how to deal with loving relatives with differing views. Furthermore, the organization was thorough and careful, without being hamstrung by bureaucracy. They had a committee of doctors to ensure that an applicant's medical records supported what they said about their quality of life, and an experienced lawyer who set the rules to keep us on the right side of the law.

However, on my way home from work on February 25, 2009, a call from a colleague came to me: "They've arrested Larry!" Larry was the medical director of the group and a close colleague. My first sight when I arrived home was of my beautiful red front door with the glass completely shattered. As I walked up the path and into my darkened house, a voice yelled "Put your hands up in the air!" I was surrounded by burly policemen and a man in a gray suit. For the first time in my life, I got the full meaning of the Miranda rights: "You have the right to..." and so on. Once I was handcuffed, the man in the suit introduced himself; he was from the Georgia Bureau of Investigation and was intending to extradite me from Baltimore to face charges of assisting in a suicide of John Celmer. Would I like to talk about it? No, of course I wouldn't, but it brought back memories of John, who had gone through numerous operations to heal cancers on his jaw and throat. After the last one and subsequent radiation, he had lost part of his jaw and was in constant pain. The doctors told him there was nothing more they could do for him, and after examining his medical records, FEN's medical committee concurred.

John and I had long conversations about his family, his anger and despair, and the morality of cutting short his life when there was no hope left. When the talk turned to theology, I referred him to a volunteer who was also a committed Christian. John eventually concluded that the Lord would forgive him. The volunteer visited and explained the process, advised John that he would have to purchase the inert gas and the hood, and that after instruction John would be responsible for turning on the gas (or deciding not to, as some people did). My last contact was to ensure he understood the process and that he always had the choice of whether this was right for him.

It is hard to remember the exhilaration and relief I felt at being released on bail. I was also aware that an expensive attorney, paid for by FEN, a friend who owned property that could be put up for bail, and my white skin had played a major part in avoiding lengthy imprisonment. Since then, I have looked with more empathy at people locked up and violated before trial, then taken away and forgotten in the jails of Baltimore, Forsyth County, and all over this land. I was only incarcerated for a few days and protected from the violence of jail, but it had lasting effects on me. It was a horrible experience, and it gave me a degree of empathy for the men and women whose imprisonment takes away their livelihood, their homes, their dignity, and often their family.

Diana and Jeff's Story

Our journey began in 2018 with Jeff's diagnosis of mild cognitive impairment. We knew that we would be living with this terminal disease for which there were no satisfactory treatments. We knew that it would gradually rob him of his most precious gift in life: a magnificent intelligence.

Jeff was trained as an internist and I as a nurse. We knew the inevitable progression and end point of Alzheimer's disease. Being of like minds, neither of us wanted to experience the ongoing, ever-increasing loss of his cognition, until little of who he was remained.

We gathered all the information FEN required for acceptance into the Guide Program: medical records and his personal letter of why he was seeking help to avoid the continuing loss of daily quality of life. FEN accepted Jeff into the Guide Program in April and he exited in September, achieving the deliverance that spared him the dreaded alternative.

Arriving at an exit date was the most difficult decision of all. When is too early, and when is too late? When would Jeff still have the competence to take his own life as his cognition was rapidly declining? There would be no flashing red light telling us the time had come. We had to tentatively draw our own map.

Two exit dates came and went. Each time, I approached Jeff with the feeling, "I just don't think it is time. What do you think? How do you feel?" We asked each other these questions often after circling a future calendar date. Then, we agreed on another exit date.

After the first exit was canceled, we agreed to talk weekly. "What changes, if any, have you noticed this past week? What changes have I noticed?" With each talk, we shared some examples, some seen and others only he could be aware of if he hadn't mentioned them. And, how could he chronicle changes when he couldn't reliably remember experiencing some of them even minutes hence? This was our process, our personal path.

A few days before the third and final exit date in late September, we again talked about perceived losses and how we were feeling about the upcoming exit date. I can't explain how this third time was different, but it was for both of us. We spontaneously agreed that we felt the moment had arrived. It was time. Yes, it was time. He had the certainty of intent, he had the means and the necessary mental and physical competence to cause his own death. And our hearts and minds were now one on this most difficult decision.

Jeff's exit, and the end of our 50-year marriage, was just as we had hoped: quick, peaceful, seemingly painless, and by his own hand. We never would have imagined in our many years together that we would be planning his death. Then dementia entered our life. FEN gave us the hope and peace to plan an ending of Jeff's choice, together. We supported each other, as always before.

Peacefulness Matters

I have been a very long-time proponent of the right to die. I am 83 years old, and the time has come to end my life. At 15 years old I suffered a severe traumatic brain injury from a fall with a horse. I was left with various disabilities but persevered with a normal life. After the accident, I functioned as a social worker, traveled to India and elsewhere, did Hindu meditation, moved to California, and was with my partner, John, for a 35-year relationship. We raised and showed dogs. John, who was uncomfortable with the method taught by Final Exit Network, is now gone, and time, meaning old age, is finally getting to me. Derek Humphry's groundbreaking book, *Final Exit*, and T*he Peaceful Pill Handbook*, by Drs. Philip Nitschke and Fiona Stewart, were important to me, as they describe peaceful means to self-deliverance. I have looked into numerous ways to end my life peacefully but found no satisfactory answer. The methods were too difficult either manually or mentally, or ingredients too hard to obtain or keep. I bought equipment for the use of inert gas; however, I had no confidence that I could manage this method. Then I discovered Final Exit Network's guides who will educate and be present throughout the process. Their helpful presence is exactly what I need. I must carry out my exit and perform it myself, but with their guidance I will make it successfully. I am forever grateful for this service. The guides are compassionate and courageous in giving this contribution to the cause of the right to die. The guides are true heroes.

~ Katie Winters, California

What's Down the Road?

BY JANIS LANDIS, PAST PRESIDENT

As the costs of elder care soar, millions of aging Americans face not only financial uncertainty but also the difficult question of how they wish to live—and die—with dignity. Hospitals acquired by private equity firms, where patient safety may be compromised for profit, nursing homes rife with reports of neglect, and an opaque health insurance industry that often denies coverage all contribute to a growing crisis. Vulnerable patients are left with fewer options and more barriers to quality care. The lack of a cohesive system for long-term support forces families into painful decisions, often with little guidance or control. In this landscape, the conversation around the right to die has gained urgency. The information below shines a light on issues related to elder care and patient safety, as well as resources that FEN provides to address these sobering statistics and to advocate for and educate on the right to a peaceful, dignified end.

Current Landscape

Hospitals and Emergency Rooms

Patients are more likely to fall, get new infections, or experience other forms of harm during their stay in a hospital after it is acquired by a private equity firm. [Source: Harvard Medical School]

NBC News recently estimated that 40% of America's emergency departments were overseen, staffed, or managed by companies owned by private equity firms. A resulting Senate inquiry showed emergency medicine staffing companies "may be engaging in cost-saving measures at the expense of patient safety and care."

Nursing Homes

Approximately 1.6 million people live in nearly 17,000 licensed nursing homes, and another estimated 900,000 to one million live in 45,000 residential care facilities. Research suggests that the 2.5 million vulnerable individuals in these settings are at much higher risk for abuse and neglect than older persons who live at home. [Source: National Institutes of Health]

Health Insurance

Insurers' denial rates—a critical measure of how reliably they pay for customers' care—remain mostly secret to the public. There's nowhere that a consumer or an employer can go to look up all insurers' denial rates—let alone whether a particular company is likely to decline to pay for procedures or drugs that its plans appear to cover. [Source: Pro Publica]

Facing Financial Ruin as Costs Soar for Elder Care

The United States has no coherent system for providing long-term care, leading many who are aging to struggle to stay independent or to rely on a patchwork of solutions. [Source: *New York Times*]

Navigating the Challenges

With more medical interventions, more complex choices about assisted living facilities, and more end of life options, it is increasingly important to have access to informed and unbiased experts.

You can count on Final Exit Network to provide those resources. We charge no fee for any of our services and receive no commissions from any institution.

Some of these resources include:

- A robust website which provides a wide range of information on patient rights, end of life options, and other related topics.
- Free access to our trained volunteers. Our volunteers can give advice tailored to your specific needs on any of the topics discussed on our website.
- Support for healthcare representatives when medical providers or residential facilities are refusing to honor the patient's advance directive.
- Speakers who are available at no cost to meet with any group to discuss death and dying issues.
- A quarterly magazine covering emerging issues, patient experiences, and additional resources.
- Exit Guide services for those who apply and meet our criteria.

For more information on FEN resources, visit our website at www.finalexitnetwork.org or call 866-654-9156.

Death and Dying in the Media

-Lewis Cohen-

Winter's End: Dementia and Dying Well
(Oxford University Press, 2024)

This valuable book is a welcome addition to the growing corpus exploring the challenges of dealing with a dementia diagnosis. Physician Lewis Cohen has found an admirable subject in Dan Winter and his husband, John David Forsgren: the poignant journey of a 57-year-old man in his prime exploring his end of life options. The meticulously researched result is based on nine months of audio interviews with Winter and Forsgren in 2020–21, subsequent interviews with Forsgren after Winter's death, and interviews with approximately one hundred palliative medical practitioners, legal scholars, bioethicists, social workers, nurses, neurologists, psychiatrists, and other experts. Cohen generously includes himself in the narrative as he clarifies end of life terminology, differentiates various forms of cognitive decline, and cites current research.

"Dan had wanted to make a political statement through his death and hoped to accomplish this by candidly chronicling his story...he was not oblivious that euthanasia, VSED, medical assisted dying, palliative sedation, and lethal overdoses or other forms of rational suicide defy traditional legal/ethical normative frameworks. Dan realized that as societies reaffirmed their position on these practices, they must strike a balance between individual autonomy, medical ethics, and the protection of vulnerable populations. However, he also knew that time was running out and he needed to make choices for himself."

Frustrated that MAID does not include supporting Alzheimer's patients, Winter unequivocally stated, "I believe that giving this option [death with dignity] to individuals who have Alzheimer's is going to make their lives better as they live with this disease."

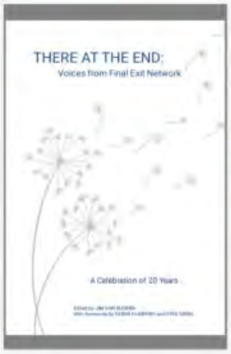
Cohen has written extensively about FEN in his masterful 2019 book *A Dignified Ending: Taking Control Over How We Die*. Heavily footnoted, with an index and six pages listing contributors, *Winter's End* is a remarkable accomplishment: accessibly written, sensitively nuanced, and highly recommended for all of us concerned about the possibility of cognitive decline.

- Film by Pedro Almodóvar -

The Room Next Door (2024)

Almodóvar's first full-length English language feature film is based on the second half of Sigrid Nunez's 2020 novel *What Are You Going Through*. Ingrid (Julianne Moore), a writer who has just published an autobiographical novel about her fear of death, reconnects with her war correspondent friend Martha (Tilda Swinton), who is dying of cervical cancer. Martha, who is haunted by being estranged from her daughter, soon asks Ingrid to accompany her to a rented home where she plans to end her own life with a "euthanasia" pill procured on the Dark Web. She explains that when the time feels right she would like to have someone in the room next door. Despite Martha's careful plans to ensure that Ingrid won't be implicated, an overzealous police officer harasses Ingrid about her involvement.

Perhaps by design, perhaps not, the dialogue is stilted, the actors unconvincing, everything feels artificial. Despite his usual attention to high style and bright colors, the director's intentions remain unclear. What might have been a measured drama about life, death, and the responsibilities of friendship feels like a superficial intellectual exercise, but to what end? Overstated references to Edward Hopper's painting, "People in the Sun," and to John Huston's film adaptation of James Joyce's novella *The Dead* further undermine the proceedings. Seemingly **not** a debate around the right to die, perhaps an investigation of female friendship, the film's lack of focus—or even conflict—are surprisingly unsatisfying.



Get your copy of the FEN anthology *There at the End* today!

Now available at both lulu.com and via Amazon.com!

$15 + s/h per book
$5 for e-book (lulu.com only)

FinalExit
NETWORK

PO BOX 10071
TALLAHASSEE, FL 32302

NON PROFIT ORG
US POSTAGE PAID
MONTEZUMA IA
PERMIT NO 30

2024–25 Final Exit Network Board of Directors

Final Exit Network Staff

Mary Ewert, Executive Director
Lowrey Brown, Exit Guide Program Director
Michelle Kalapodis, Executive Assistant
Heike Sanford, Member Services Coordinator

Final Exit Network

PO Box 10071
Tallahassee, FL 32302
866-654-9156
EIN: 80-0119137
www.finalexitnetwork.org
info@finalexitnetwork.org

Charity Navigator
✦ FOUR-STAR ✦

Platinum
Transparency
Candid.

Photo Credit: Sawade

As this publication was going to press, we received news that Derek Humphry, FEN co-founder, right to die pioneer, and author of the acclaimed book Final Exit, *passed away at the age of 94. We will honor Derek's tremendous legacy in the next issue and ask you to join us in expressing gratitude for all that Derek did to champion choice in dying.*