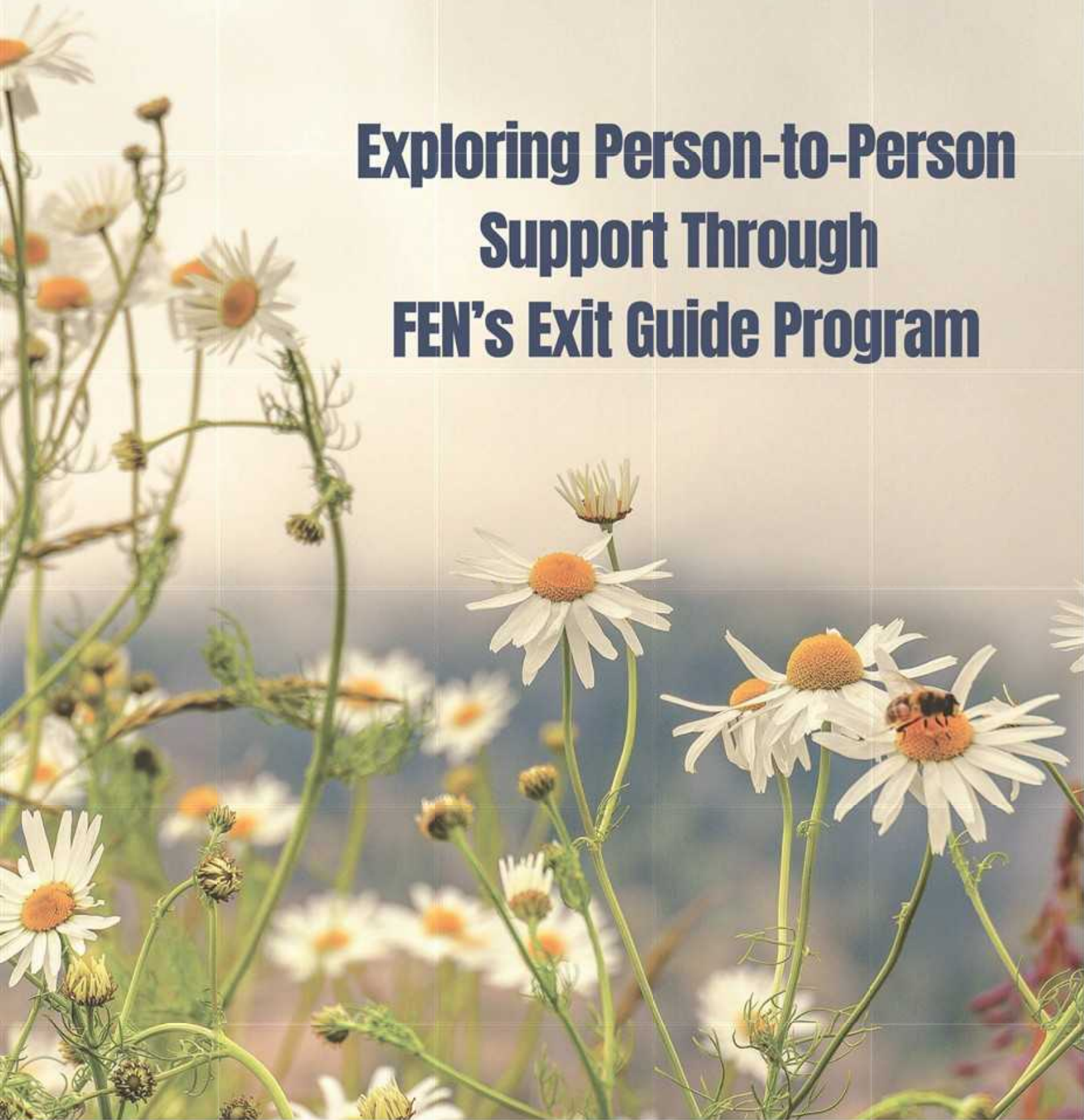
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# Final Exit Network

## Exploring Person-to-Person Support Through FEN's Exit Guide Program



*Final Exit Network (FEN)*

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## Welcome to FEN's New Operations Manager!



We are delighted to welcome Kathy Husu as our new Operations Manager. She brings extensive healthcare operations and project management experience, most recently with Mom's Meals and United Health Group, where she led strategic initiatives focused on improving quality, efficiency, and patient outcomes.

Kathy is thrilled to join FEN and advance its important mission, which resonates deeply with her. "I felt it firsthand in caring for my mom with multiple health conditions," she shares.

Please join us in welcoming Kathy!

# From the Board President and Executive Director





We are delighted to dedicate our fall magazine to the cornerstone of Final Exit Network's mission: the Exit Guide Program (EGP).

The EGP provides compassionate, person-to-person education and support for people exploring pathways to a chosen death. While Final Exit Network is grateful for the continued growth of Medical Aid in Dying across the country—and for options such as Voluntary Stopping of Eating and Drinking and Voluntary Assisted Dying in Switzerland—FEN was founded to serve people who want, and deserve, choice in dying—now.

FEN's trained volunteer coordinators help individuals understand and navigate the choices available to them. And our volunteer exit guides support competent adults seeking a safe, reliable, and comfortable way to end their lives on their own terms—particularly when other end-of-life options are unavailable to them.

Together, our coordinators and exit guides provide the compassionate, individualized support that has always been at the heart of FEN's mission.

In this issue, you'll find more information about the EGP, the volunteers who make it all possible, and the impact it continues to have for the families we serve. And our work is also made possible by the ongoing support of our members and donors! A heartfelt thank you goes out to our volunteers and supporters who bring our critical mission to educate and support those who want choice in dying to thousands every year.

In Gratitude,

Anita Winsor | Board President

Michelle Witte | Executive Director

# On His Own Terms: Bringing My Grandfather's Final Year to the Stage

BY CHRIS BLACKWOOD, PLAYWRIGHT

In September, I had the opportunity to debut *The Countdown*, a solo show I've wanted to create for nearly eight years, at the Philadelphia Fringe Festival.

The show tells the story of my grandfather, Jim Chastain, a longtime right-to-die advocate and former president of Final Exit Network. When he was about 90, he told our family that he had chosen his 92nd birthday to end his life. He wasn't terminally ill or in crisis. He believed deeply in personal autonomy at the end of life, and he wanted to approach his own death deliberately, openly, and on his own terms.

*The Countdown* explores what it was like to be his grandson during that final year—knowing exactly how much time we had left and wrestling with what it meant to love and support someone making such an extraordinary decision.

The show combines comedy and storytelling with family photos, emails, archival material, and recordings of my grandfather himself.








*Photos from Chris Blackwood's original play,* The Countdown, *which debuted at the Philadephia Fringe Festival in September 2026.*

Performing the first two full runs at Philly Fringe was an incredibly meaningful experience, particularly hearing from audience members afterward who connected the story to their own experiences with aging, death, family, and autonomy. *The Countdown* remains a work in progress, and I'm excited to continue developing it and bringing it to new audiences.


## Twenty Years. Countless Stories. One Remarkable Anthology.




We get so many questions about the numerous paths to a very personal decision. *There at the End: Voices from Final Exit network shares the* stories of clients, volunteers, and family members who started their journey with FEN. Do you have your copy yet?

Available exclusively at lulu.com.
Digital version $5
Printed paperback version $15

"The first-person accounts by FEN clients and volunteers are riveting, poignant, and inspiring."

~Chris Palmer, Author
*Achieving a Good Death*

"FEN's cardinal virtues shine through in this collection of compelling cases shared by clients, founders, and volunteers."

~Thaddeus M Pope, JD, PhD, HEC-C, Author
*The Right to Die: The Law of End-of-Life Decisionmaking*

"The stories depicted in this anthology strongly underline the value and importance of FEN's work for the right to die in the United States and in the world."

~ Rob Jonquiere, Executive Director
World Federation of Right to Die Societies

"Clergy, chaplains, and spiritual directors who deal with end of life issues will find this anthology a vital resource."

~Reverend Jim Mitulski, Pastor
United Church of Christ

# The Exit Guide Program: A Crazy and Compassionate Idea

BY LOWREY BROWN, EXIT GUIDE PROGRAM DIRECTOR

When many of our clients first hear about the Exit Guide Program, they're amazed to learn that it exists. And that's not surprising. In our youth-obsessed, death-denying culture, who would come up with the idea of traveling around the country, visiting people in their homes at their most vulnerable moments, teaching them how to conclude their own lives, and offering to come back and sit with them when and if they decide to do so?

Well, fortunately, our Final Exit Network forebears did. Over twenty years ago they started educating people one by one, and thereby built the Exit Guide Program, scraping together what donations they could and often using their own resources to make it happen. It has not been all smooth sailing (what social movement ever is?), yet after more than two decades, the Exit Guide Program continues to support individuals facing intractable medical conditions who want to shape their own ending, and this magazine issue is dedicated to celebrating that crazy, compassionate idea.

From its inception, Final Exit Network has provided education and support to individuals unable to access choice in dying through the medical system. A few decades ago, that was almost everyone, though some compassionate doctors would surreptitiously support dying patients who wanted to hasten the process. But recent years have brought some improvement. A number of states have passed medical aid in dying laws for the terminally ill; voluntarily stopping eating and drinking has been discussed in medical journals with clinical care guidelines outlined; the option of traveling to Switzerland for voluntary assisted dying has become more widely understood and used.

Yet despite these expanded medical opportunities, many who want choice in dying are still not served.

Medical aid in dying in the US requires a terminal diagnosis, a prognosis of six months or less, and decisional capacity at the moment of ingestion—which rules out anyone wanting to apply based on dementia and excludes the person in advanced old age whose body is failing in six directions without any of them being terminal. As for the Swiss option, the fees alone run approximately $15,000, and you have to get on an international flight at a point in your life when you are least able to do it. Closer to home, voluntarily stopping eating and drinking is available to any competent adult, but it's a team sport—you need medical support and personal care, and it typically takes ten to fourteen days.



This is where Final Exit Network steps in. The Exit Guide Program's coordinators (who are the first point of contact for those who reach out to us) provide person-to-person information and direction about options both inside and outside the medical system. So, people who want to and are able to end their lives with medical support can connect with the resources they need, while those who can't access or don't want a medically facilitated path and who meet FEN's criteria for support can apply for exit guide services, where the guides provide education on communicating about and planning a responsible self-deliverance. Guides can even provide a compassionate presence, if desired, at the time of an individual's chosen death.

The Exit Guide Program is a powerful demonstration that choice in dying is a reasonable, rational, self-compassionate option, and that your choice does not have to depend on the approval of healthcare providers. In the pages that follow, some of our volunteers share their experiences from serving the people who turn to us for information, education, and guidance. There are plenty of heartwarming stories, but, like Final Exit Network's history, our volunteers' work is not always smooth sailing.

Before I turn the mic over to them, I want to emphasize that what our volunteers do is hard work. They spend many, many hours on the phone. Our volunteers patiently repeat themselves (and repeat themselves) to people in early-stage dementia who are struggling to keep details straight. They agonize over medical records that hint at what the applicant describes but are open to interpretation. They get accused of being cold and heartless (and other things we will not print) when they must turn away applicants who do not meet our criteria or whose situations are not safe. They answer questions from family members and loved ones who may be feeling suspicious or angry. They calm fears. They correct misconceptions. They facilitate crucial communication.

May the stories that follow be a celebration not only of those we serve, but also of those who serve. They are the bedrock of the grassroots, person-to-person support Final Exit Network provides.

# the Exit Guide Program

## How Does Exit Guide Support Work?

If you're interested in applying for exit guide services, you'll first speak with one of our volunteer coordinators by telephone to discuss your particular circumstances. The coordinator will work with you to evaluate whether you might be an appropriate candidate for guide services and will discuss other options for hastening death that are available to you.

If you decide to move forward with an application, the process involves writing a personal statement that describes your condition, answering a short questionnaire, and then collecting medical records that document a doctor's diagnosis of that condition. You'll send these materials to FEN.

Once your coordinator judges that it's appropriate to move forward, the next step is a telephone interview with another FEN volunteer, during which you'll discuss your condition, your circumstances, and your wishes.

Your coordinator then assembles the interview report and your paperwork, and submits the application to FEN's Medical Review Committee, an interdisciplinary team of healthcare professionals who ensure that your application meets our medical criteria.

If the Medical Review Committee finds that your application meets our criteria, you'll be paired with a FEN guide who will evaluate your circumstances, support you in initiating difficult conversations with your closest loved ones, and work with you in planning a responsible chosen death. Guides do not provide physical assistance or any means for ending your life.

FinalExit NETWORK

### Exit Guide Program Application Process



**Speak with a Coordinator**

Start by speaking with a Final Exit Network coordinator, who will work with you to evaluate whether you might be an appropriate candidate for guide services, and will discuss other options for hastening death.

**Apply (if desired)**

If you choose to move forward, you will complete a questionnaire, provide a personal statement that describes your condition(s), and collect medical records that document a doctor's evaluation of the condition(s).

**Interview**

You will participate in a phone interview with another volunteer to discuss your condition(s) and circumstances.

**Medical Review Committee**

Your application and documents are carefully reviewed by FEN's interdisciplinary team of healthcare professionals who ensure that your application meets our medical criteria.

**Exit Guide Assigned**

If the application passes medical review, an exit guide will be assigned, who will evaluate your circumstances, support you in initiating difficult conversations with your loved ones, and work with you in planning a responsible chosen death.

**"It makes perfect sense to me that a 'good life' can reasonably be followed with a 'good death' with grace and dignity. That is why Final Exit and all it embraces is what I am choosing."**

**~Applicant to Guide Services**

# A Closer Look: FEN's Coordinators

*For many people, a conversation with a FEN coordinator is the first step toward understanding their options. FEN's volunteer coordinators respond to phone calls and website inquiries from across the United States. They answer questions, discuss available options, provide educational resources, and connect individuals with additional information relevant to their situation.*

*Support may include guidance related to medical aid in dying (MAID), voluntarily stopping eating and drinking (VSED), dementia planning, voluntary assisted dying in Switzerland, advance directives, or other end-of-life choices. Coordinators help people understand what options may be available where they live and what steps they may wish to consider next.*

*Most importantly, coordinators provide a compassionate, knowledgeable voice during what is often a difficult and emotional time.*

## Flexibility: Necessary for Choice in Dying

BY JIM VAN BUSKIRK, COORDINATOR

"Is this still the policy of FEN? *Though we recognize the extreme suffering caused by mental illness, we do not accept applicants whose primary medical complaint is mental illness.*"

Receiving this query, I realized the simple answer was yes. But I also recognized that nothing about any initial inquiry is straightforward. Some callers are forthcoming about their entire life story, including their health and medical issues. Others are reticent to reveal much of anything. This caller (whom I'll call Sam) shared a lifetime of psychiatric and physical trauma, including suicidal ideation. He was trying to get to Switzerland but had limited financial means and had been referred to FEN from the Hemlock Society of San Diego.

I listened sympathetically and attempted to gain more information. How extensive was the physical component to his suffering? I explained other options, including VSED and the use of inert gas. I very cautiously suggested if the physical aspects of his suffering were persuasive enough, he might qualify for FEN's Exit Guide Program, but I wouldn't want him to jump through the hoops of FEN's application process knowing his application might not be accepted. He was willing, he assured me, since he was already jumping through similar hoops for a Swiss clinic. After many phone conversations, mostly around which of his extensive medical records he should submit, his extremely well-organized application materials were received and his application was submitted to FEN's Medical Review Committee (MRC).

Throughout the process Sam was upbeat and appreciative and realistic about the outcome. Disappointingly, but not unexpectedly, his application was denied: the "MRC is sympathetic that Sam is suffering, has been through most of his life, and that more recent physical problems and chronic pain add to his suffering from his chronic depression. Because FEN cannot accept clients whose primary diagnosis and/or reasons for applying for guide support are mental-health related, we unfortunately cannot recommend him for guide assignment."

Informing people that their applications have been denied is the most heart-wrenching aspect of the coordinator's duties. I was relieved that Sam took it so well, expressing deep appreciation for everyone's efforts on his behalf. Then he called back to ask if he could speak to FEN's Swiss Option Advisor. I forwarded Sam's paperwork, and shortly after, Sam called to tell me that they'd had a productive conversation and to once again express his appreciation for FEN's support.

While Sam's journey will not be the smoothest nor most direct path to a chosen death, if that is what he ultimately chooses, I take comfort in knowing that we took the time to explore his options with him and support him as he considered what he wanted and how he might get there. I also hope that the process itself was useful to Sam as he contemplated his options and found comfort in knowing he is not alone. As a volunteer coordinator, I do my best to connect people with the resources they need to access the chosen death option they want. When that doesn't work, I hope I am able to bring some consolation through solidarity and compassion.

## Getting to Know You

BY JILL LORENZ, COORDINATOR



As a coordinator, I've shepherded many people through the application process for guide support. One of the joys of coordinating is the intimacy that comes when people share their hopes and fears. I am always touched by the trust people place in me.

The following are two examples of people I was privileged to get to know, if only briefly (I've changed their names). Joyce was a psychotherapist in her early 70s. She lived alone and had stopped working because she was having memory problems. She wondered if FEN could do anything for her. I was a new coordinator and eager to help. I explained her options. She decided to proceed with an application for Exit Guide Services. She did not want to live with dementia.

It soon became clear that she was losing ground quickly. She would call with a question about the application process and then call a few hours later with the same question. She was experiencing a tremendous amount of anxiety, and we could both sense the urgency of her situation. While she was perfectly clear about her situation and what she wanted, she, like so many people in early-stage dementia, was experiencing short-term memory impairment. I suggested that she enlist a friend for support putting together the necessary paperwork. With that support, she was able to apply, was approved to work with a guide, and exited soon after

# and Interviewers

that. It reminded me of the Vulcan mind meld, as she was able to use her friend's short-term memory so she could exit on her own terms.

Adam was a builder who lived alone. He had been severely injured in his twenties and had lived in pain ever since. In his early seventies he called FEN when he had a diagnosis of mild cognitive impairment. He found support at meetings organized by the Alzheimer's Association and enjoyed the people there, but discovered that they weren't open to discussing chosen death. Someone took him aside and suggested that he not bring up suicide in the meetings, but to call Final Exit Network. I guided him through the application process. Though my role was limited to his application, he would often share a bit about his preparations for disposing of his property, the charities he supported, and the work he had done. When I called to let him know that his application had been approved and that he would be talking to a guide from then on, he said, "I miss you already."

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*FEN's volunteer interviewers speak with each applicant to gather a complete picture of their circumstances and reasons for applying. Through a thoughtful, respectful conversation, they explore the applicant's physical suffering, state of mind, quality of life, understanding of their situation, and reasoning behind their choice to apply. Interviewer questions also help clarify the applicant's support system, including the knowledge and attitudes of those closest to them. This information becomes an important part of the application and review process.*

## Each Interview is Different

BY JIM, INTERVIEWER

I've interviewed about fifty potential clients since I began almost seven years ago, and it's very interesting and rewarding. Every interview is different. Some people are very talkative, while others are more reticent.

The interview is an unusual process. We have standard questions, many of which are very personal in nature, and it's odd to get so personal with a stranger so very quickly, even more so because the interviewer and candidate will likely never meet or even speak with each other again.

Yet time and again, interviewers are able to establish a rapport with a candidate at this very meaningful time of their lives. The individuals are very grateful to the interviewers for giving them an opportunity to discuss topics that they may not be able to discuss with anyone else.

As an interviewer, I've learned a lot about the myriad diseases and how our bodies can turn against us. The one thing that surprises me most is the physical and mental difficulties people have endured prior to contacting us. Most people seem to make the decision to contact FEN only after trying every other option. They see us as a last resort to reclaiming some control over how to live and end their lives, and it's very satisfying to share information on options.

## Beauty and Complexity

BY PATRICK MCNEIL, INTERVIEWER



Interviewing prospective clients for FEN is very rewarding. The interview covers several areas that are important for determining whether the applicant qualifies for guide services.

In addition to gathering information on the medical reason that led the applicant to FEN, I try to assist the prospective exit guide in determining who in the applicant's life may or may not be supportive of a FEN application. To explore this, I discuss with the applicant his/her many relatives and friends scattered across the globe, as well as neighbors.

As every canyon is unique, shaped over years by interactions between water and soil and stone, so too every FEN applicant's situation is a confluence of personality and people and happenstance. Having completed many interviews, I can assure you that no two are the same. How do I capture eighty years of relationships on one page? I do my best and enjoy the journey. Some of the applicants are blessed with bountiful, loving support, while others navigate their lives alone, often with great dignity and purpose. No matter the circumstances, I always end the interview in awe of the beauty and complexity of people's lives.

## A Privilege

BY NINA KETTERING POWELL, INTERVIEWER



My role as a volunteer interviewer is challenging at times, but always deeply rewarding. FEN's interview questions are carefully designed to assess an applicant's mental competency, physical capability, and autonomous decision-making ability regarding end-of-life choices. As an interviewer, my first priority is to build rapport so applicants feel safe candidly answering deeply personal questions.

Every interview is unique. Often, a loved one is in the room, sometimes participating in the conversation as a helper. It's important to be sure the applicant still has autonomy and is accurately represented by the helper during that sort of dynamic.

While the interview can have an anxious or sad feel, it also brings moments of joy and connection. One of my favorite memories is of a dynamic, joyfully eccentric woman who spent part of our call speculating how her beloved, elderly cat might be able to physically exit alongside her.

Applicants, and any family members with them during the interview, nearly always express immense gratitude for FEN. It is a privilege to be invited into these intimate spaces. I believe that helping someone plan a peaceful, dignified exit carries similar weight and importance to planning a birth or a marriage, and I am honored to be a small part of it.

# The Unexpected Gift of a Chosen Death: Connection, Closure, and Life

BY MARY ELLEN BATES, EXIT GUIDE

As an exit guide, I have the profound privilege of walking alongside individuals as they navigate their end-of-life choices. There is a common misconception that finalizing a decision to hasten death is a purely solemn, closing chapter. Rather, in my experience working with exit guide clients, securing the means for a peaceful death frequently breathes beautiful, unexpected life into their remaining days.

When someone feels trapped and frightened by a declining medical reality, the mere presence of an "escape hatch" brings incredible peace of mind. It restores a crucial sense of agency. This relief often leads to one of my favorite outcomes: Clients reach a point where they are fully prepared to hasten their death, only to pause the process, get on with their lives, and never call us back. Recently, after one client completed her education visit and had her equipment ready to go, she wrote to us simply saying, "Thank the guide for giving me my life back." It is a powerful testament to the reality that having a choice is a deeply life-affirming intervention.

This newfound breathing room allows clients to take conscious advantage of their remaining time to connect. In fact, the conversations our clients have with their loved ones through this process are frequently the most rewarding part of the entire process, for everyone involved. When you tell the people you love the whole truth about your situation, you invite them into the most significant decision of your life instead of leaving them to find out afterward. What comes out of this honesty is often extraordinary. Things are said that would otherwise have gone unsaid, and old business gets finished. Everyone has a chance to say goodbye properly, with intention and love, rather than in a panicked hospital corridor at two in the morning.

The clarity of a self-determined timeline can even act as a catalyst for healing fractured relationships. I can think of at least a half-dozen instances where a parent and an estranged child were able to reopen communication because the client initiated a final, honest conversation. They may not suddenly become close, but they both use the opportunity to say the things that truly matter. I never tire of a client calling me to say, "You won't believe it, but my formerly estranged son is flying out here to spend a week with me."

This precious time also allows for deep internal reflection. Once the anxiety of an unpredictable end is lifted, clients can focus on emotional and spiritual closure. Some have used this space to pursue psychedelic-assisted therapy. After a few sessions, one client called me to share a beautiful revelation: "I'm falling in love with myself again."

Witnessing someone reclaim control over their dying process is undeniably rewarding. It sounds strange to say out loud, but we teach people how to die so they can go on living while they still want to—empowering them to fill their final chapter with intention, connection, and a full heart.

**"When my husband applied for and qualified for exit guide support, there was never any pressure (to select any particular choice).**

**"From the coordinator through the interviewer through the exit guides, and even after my husband's window of opportunity passed, I was able to stay in touch with the coordinator and the senior guide to receive other information and support. The channels of receptivity, communication, and support were so different from any other end-of-life avenue we worked with. That was my reality, and that is why I volunteer on the Medical Review Committee, serve on the board, and am a donor."**

**~ Beverly Thorn**

# FEN's Exit Guide Services

## Final Touches

BY LOWREY BROWN, EXIT GUIDE



My fellow guide and I arrived for the exit of a couple. We walked up around the side of the house that was perched on a hillside overlooking small farms and residences. The wife offered us some freshly baked cookies while she packaged the rest along with food she had prepared and was putting in the freezer. Their son, who had visited recently to say goodbye, lived in another state. He would call the authorities to notify them of his parents' chosen deaths and then make the long drive back to clean out their house. She wanted to be sure he had wholesome food to eat while doing so, as well as some homemade cookies, to see him through what would be a big chore.

Another guide described arriving for an exit to find her client hanging a lovely coat to dry. The client had washed it so it would be ready for the next pair of shoulders it would keep warm in the winter wind. One client left a bowl of fresh berries on a table by the door with a note indicating it was for the officers and medical personnel who would respond to her chosen death. Prior to their exits, we find clients washing the last of the dishes and putting them away, taking out the trash, or replacing the empty tissue box on the side table. They have been found watering the houseplants or the garden.

In my bleaker moments, surveying the chaos of my desk, the shower shelf barely hanging with half its suction cups, the stuff that seems to metastasize in my closets, I fantasize about walking away and letting it all be someone else's problem. Interesting that those who really are about to walk away—permanently—instead choose simple acts of generosity as their parting gift to those who will come behind them. There is something so humble and quiet and beautiful in these gestures. It seems that the things we do to care for each other in life are also the things we do to care for each other in death. May you be warm. May you be well fed. May the garden give you its bounty. May you be comfortable in this space; though I am gone, I have prepared it for you.

## A Story of Grace

The following is an excerpt written by a former exit guide that is included in FEN's 20th anniversary anthology *There at the End: Voices from Final Exit Network*. It is the story of Grace, written by Brian R.

*As exit guides, we have many very poignant experiences being with people as they are preparing to die. Each is unique and makes us feel fortunate to be able to support people who have been enduring suffering and pain and want to manage their last days.*

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*When we arrived, we noticed the house was filled with objects, both sacred and mundane. Grace sat in her big chair—now her only place—and, without any trepidation, reported that "today is the day and I want to go home." Grace had lived the last ten years of her life in excruciating pain... Each day was a difficult struggle. Fortunately, she had two friends who provided moral and physical support through her trials and who were present at the exit.*

*After we completed our formalities, Grace said she wanted to do a little drumming and chanting. Her room had a number of instruments, which she began to play, beginning by breathing into them with the sound of a soft breeze through an open window. She also sang with an unwavering voice as pure as crystal, a stark contrast to her failing body that could barely hold its own weight. It was beautiful and allowed us all to feel the energy build in the room.*

*After the drumming, Grace seated herself in her favorite chair to sing a song... "All I ask of you is to remember me as loving you," she said. She sang the entire song with a smile on her face so that we could all share her love and know she was prepared to die. She died peacefully over the next fifteen minutes.*

*What a gift it was to witness such peace and equanimity rooted in a greater sense of community and spirit, with the dignity and courage to approach death with ceremony and confidence—heartfelt, natural, and relaxed. It made us realize the importance of what we do and how fortunate we are to be able to do it.*

To purchase your digital or printed copy of *There at the End: Voices from Final Exit Network*, visit lulu.com.

## The MRC's Function in a Client's Application Process

BY ROBERT, MRC CHAIR

The Medical Review Committee (MRC) is FEN's interdisciplinary team of healthcare professionals whose responsibility is to ascertain that an applicant's medical records, personal statement, self-report on how their condition is affecting their quality of life, and the information they shared with a FEN interviewer meets FEN's medical criteria for becoming a supported client. The purpose of this review, which is one of multiple review points in a client's process, is to help ensure that those we serve are making a carefully considered and rational choice, and to ensure that FEN is acting ethically and responsibly.

As FEN's volunteer training manual states, criteria for guide support includes the applicant's being mentally competent and having "existing or reasonably anticipated unbearable suffering or an unacceptable or intolerable quality of life with no reasonable hope of improvement." Applicants are advised to wait to apply until they expect to exit within a year, not as an insurance policy for the future. Categories of acceptance include serious physical disease (which may or may not be considered terminal), chronic severe pain, dementia, and a constellation of conditions. The latter may be chronic, irreversible, often old-age-related but not fatal conditions, and includes consideration of factors that contribute to an applicant's sense of a "completed life."

FEN does not accept applicants with primary mental health diagnoses. The MRC recognizes that anxiety and depression often accompany physical illnesses and that a person's past or current mental health diagnosis may not be the primary reason for their desire to control how they die under their current circumstances. Because of these factors, a secondary mental health diagnosis does not automatically disqualify a person for guide support.

Currently, the MRC is comprised of five physicians and two nurses, all with significantly different backgrounds and experiences, and two psychologists with backgrounds that include chronic pain management, one of whom currently chairs the committee. The MRC's membership is interdisciplinary because FEN's criteria for guide support include both medical and psychosocial considerations. Two MRC members and the MRC chair review each application, and if it meets one of the four criteria for guide support, the applicant is then recommended for guide assignment and ongoing review and support.

## The Dilemma of Medical Review When Assessing Dementia Applications

BY BEVERLY THORN, MRC MEMBER

As a member of the MRC, I have noticed the growing number of applications listing dementia as the reason for seeking exit guide services. It shouldn't surprise me, as the US has approximately seven million people living with dementia, and they have few options for choosing the timing and circumstances of their deaths.

An individual cannot qualify for medical aid in dying (MAID) based on a dementia diagnosis, even in the fourteen jurisdictions where MAID is legal. This is because by the time someone with dementia is within six months of death (a criterion for MAID eligibility), they have lost their ability to make their own medical decisions (also a MAID criterion). And their healthcare representative cannot make that decision for them, even if they have specified the desire for MAID in their living will prior to losing decisional capacity.

FEN also requires that applicants retain their ability to make medical decisions, but does not require that a person be judged to be within six months of death.

When faced with dementia, people want to live as long as possible, but also fear losing their window of opportunity by waiting so long that they have lost cognitive capacity to make choices about their death. In the MRC, we see the dilemma of these excruciating choices play out in their applications for exit guide services.

One common misunderstanding is that the diagnosis itself and dementia are the same thing. They are not. With the advent of increasingly sophisticated biomarker tests, particularly for Alzheimer's, a person can get a disease diagnosis before they show any symptoms of dementia. In other words, you can be diagnosed with a dementia-causing disease but not yet have the cognitive impairment that is the hallmark of dementia. For example, Alzheimer's disease, associated with sixty to eighty percent of all dementias, can be present for decades before the development of cognitive impairment. As of 2025, a blood test for the protein associated with Alzheimer's disease was approved by the FDA and can be positive long before cognitive decline occurs. Similarly, other biomarker tests (lumbar puncture or a special CT scan) can confirm the presence of the biological markers for Alzheimer's disease, but they don't verify the cognitive decline characteristic of dementia.

To approve an application for exit guide services, the MRC needs to see evidence of cognitive impairment itself, not just evidence of a dementia-causing disease. So, as concrete as the results of

# Medical Review Committee (MRC)

a biomarker test may appear, the MRC needs to see the results of cognitive testing. Some common standardized cognitive tests are the Montreal Cognitive Assessment (MoCA), the Mini-Mental State Exam (MMSE), or a full neuropsychological test battery by a psychologist.

The task of the MRC requires both the head and the heart. We support everyone's right to choose the timing and manner of their death, yet our standards require certain documentation. Brain disorders that cause dementia are often long-term, rob the person of the essence of their personhood, and are somewhat unpredictable in their time course. Applicants trust us to be wise enough to make decisions that allow them to choose a death before they lose their window of capacity at the same time they are already experiencing diminished abilities to think, plan, and problem solve. It is a delicate balancing act that has no precise answer. We feel the weight of our decisions with each applicant we review.

## Remembering Long-Time, Treasured FEN Volunteer Deborah McElhannon

FEN learned in late September that longtime volunteer Deborah McElhannon died unexpectedly. Exit Guide Program Director Lowrey Brown shares:

*She always made me smile. Even when talking weakly from a hospital bed she could merrily describe giving away her automatic cocktail-maker to her daughter. (Who knew such a thing existed?) She wasn't wringing her hands or fighting the change. She was sharing the pleasure it had brought...and letting it go. May I learn from her to take life's inevitable changes and losses with even half as much grace as she did. She kept a low profile on the Medical Review Committee but was a rock-solid foundation. You could rely on her to be careful and thoughtful; she managed somehow to be both generous and exacting in her evaluations.*



*When a past MRC chair began experiencing health issues, Deborah stepped into the background and managed the flow of applications, which was more of a load than she ever acknowledged. To think that I will never hear her laugh again...but I did hear her laugh, and my life is richer for it. Rest in peace, Deborah.*

## Did you know FEN has members and supporters in all 50 states, DC, and 12 countries?




FEN Executive Director Michelle Witte traveled to Alaska this summer and met and made connections with the folks from End of Life Options Alaska and Alaska End of Life Alliance. She was thrilled to learn about the great work their team is doing to bring medical aid in dying to Alaska. And of course, it was wonderful to share with them all FEN can offer the great people of Alaska! Great connections and learning together...a win-win.



*Ere Corveau, End of Life Doula and Deathcare Educator and FEN ED Michelle Witte in Alaska*

## World Federation of Right to Die Societies (WFRtDS) Launches New Publication

Final Exit Network is proud to stand with the World Federation of Right to Die Societies and member organizations around the world that believe individuals should have meaningful choices at the end of life. We are also delighted to be a Founding Society Sponsor of *WFRtDS Quarterly,* a new international digital publication highlighting news, developments, research, advocacy, and personal perspectives from the global right-to-die movement.

We invite our readers to consider subscribing to this new publication, which will also provide important revenue support for the work of WFRtDS. More information is available at wfrtds.org/magazine-launch.

Thank you for helping build this new international publication and, importantly, for helping to ensure that the voices and experiences of our movement are shared across borders.

# The Dementia Tsunami May Not Be Inevitable

BY DENA DAVIS, JD, PHD, FEN BOARD MEMBER

We are, according to many reports, about to be facing a "tsunami" of dementia, primarily driven by LOAD (Late Occurring Alzheimer's disease). According to the Alzheimer's Association, seven million Americans are now living with the disease, with nearly thirteen million expected by 2050. From a healthcare, caregiving, and economic perspective, the numbers are truly scary. Health and caregiving costs for people living with dementia are expected to reach one trillion by 2050. We are already doing a really bad job of providing care for people with dementia—how will we manage if the numbers get worse?

This sobering prediction is not mysterious. We know that age is the most important risk factor for getting Alzheimer's. After World War II, people got busy creating families and having babies, the so-called Baby Boom. Those "boomers" were also the first cohort to enjoy the protections of penicillin, polio vaccines, and other public health miracles. So most of us survived, and we went on to live longer lives than our predecessors. In 1900 life expectancy was only 49 years on average, while today it is 79 years. The population aged 80 years or older will double between 2025 and 2050.

All this is true, but a recent article in *Journal of the American Medical Association*, by P.J. Eric Stallard, Svetlana V. Ukraintseva and P. Murali Doraiswamy, all from Duke University, argues that we need a more nuanced approach to calculating the future burden of Alzheimer's disease. The main concept here is the difference between prevalence rate and base rate. The base rate —the number of people 80 or older—will double, barring a huge pandemic or other catastrophe. Does that mean that the number with Alzheimer's will also double? Not necessarily, because the prevalence (or ratio or fraction) of people with Alzheimer's within that age cohort might rise or fall.

In fact, the good news is that while the number of older people does increase, the prevalence of Alzheimer's is actually falling. Each birth cohort, at twenty-year intervals, seems to have a lower prevalence of Alzheimer's. Thus, the Duke researchers suggest that if trends continue, rather than doubling the number with dementia by 2050, the increase would be more like ten to twenty-five percent.

Researchers speculate why the prevalence rate is falling. A recent study showed an association between three key health factors at midlife: People without hypertension or diabetes, and who did not smoke, had on average thirteen more years of life without dementia. (Forty-two percent of Americans smoked in 1965, compared to fewer than ten percent today.) Increased education and better nutrition are also associated with a smaller risk of dementia. Other studies show an association between older people receiving vaccines against flu and shingles and being less likely to get Alzheimer's. On the other hand, rates of diabetes are climbing.

Hopefully, the prevalence rate will continue to fall. What stands out to me in these studies is that to the extent that these studies are actually causative, not just associations, they are tethered to other factors that bedevil health in America. Poor air quality is associated with higher risks of dementia; marginalized communities are disproportionately exposed to lead, air pollution, hazardous waste, and extreme heat. It's hard to get good nutrition when one's food stamps are being cut. It's hard to keep track of one's blood sugar when you can't afford health insurance or you can't buy gas to get into town. There's a lot we don't know about dementia. But there is a lot we do already know, and economic justice can go a long way to addressing the risks we can do something about.

**Per NIH statistics, health care, long-term care, and hospice costs for people with dementia are projected to reach $409 billion in the US in 2026.**

**Additionally, over 12 million family members and friends provide unpaid care, with economic values reaching hundreds of billions of dollars.**

—Alzheimer's Association's
*2026 Alzheimer's Disease Facts and Figures*

# A Contingency Plan for a Life I Still Want to Live

BY JOEL A, FEN MEMBER

My journey to Final Exit Network began with a diagnosis I never expected to receive: frontotemporal dementia, or FTD.

I am a husband, father, grandfather, Christian, and professional engineer. My wife, Anne, and I have spent much of our adult lives together, including many years living and working overseas. We have raised a family, built a life together, experienced suffering, and seen God answer prayers in ways I never expected.

Serious illness is not new to me. For thirty-three years, I lived with ankylosing spondylitis, a chronic inflammatory disease that at times caused extreme pain and disability. For more than ten years, I was unable to work and received Social Security Disability Insurance. For about two years, I used a wheelchair.

There were times when the pain became so severe and seemed so unending that I experienced suicidal thoughts. When my doctors prescribed stronger pain medication and brought the pain under better control, those thoughts subsided. That experience taught me that even overwhelming suffering can sometimes change when the underlying problem is treated more effectively. My illness was also not terminal, so there was always the possibility that my condition could improve—and eventually it did. In 2021, after decades of illness, my symptoms unexpectedly went into complete remission. That remission gave me years of life without the pain that had once dominated my days.

It taught me never to assume that suffering today means there can be no better tomorrow.

FTD, however, confronted me with a very different problem. Dementia does not simply threaten the body. It progressively threatens memory, judgment, language, empathy, personality, independence, and ultimately the ability to understand what is happening. It can also impose enormous psychological, physical, and financial burdens on a spouse and family.

Anne has already cared for me through decades of illness. When I began seriously studying what advanced FTD can do not only to the patient but also to the caregiving spouse, I realized that I needed to think about the future while I was still able to do so clearly.

For me, having an end-of-life option does not mean I want to die. I want to live. I continue to hope for more good years and better treatments, and I continue to pray that God may heal me.

Having a contingency plan simply means that I do not want dementia to make every decision for me.

People do not buy life insurance because they hope to die. They buy it to protect the people they love if the worst happens. I think of my contingency plan in much the same way: Having an option available does not mean I have decided to use it.

There is tremendous peace in knowing that I am not alone as I think through these questions.

This broader journey also led me to write a book, *A New Option for Dying with Dementia: Christian Conscience, Terminal Illness, and the Freedom to Choose*.

I wrote the book particularly for Christians because suicide remains one of the strongest taboos in Christian culture. The book asks a narrow but difficult question: Could a Christian facing an incurable and ultimately fatal dementia diagnosis, in rare circumstances and after prayer, counsel, and careful reflection, morally choose to hasten death rather than live through the most devastating stages of the disease?

I do not argue that everyone should reach the same conclusion. One of the book's central themes is humility. People of sincere faith and conscience may reach different conclusions about death and suffering. But they should at least be allowed to ask the questions.

That willingness to ask difficult questions is one of the things I appreciate most about FEN; they are willing to have conversations that much of our society still avoids. Terminally ill people deserve honest information. They deserve compassion. They deserve to understand their choices. And they deserve to be treated as human beings rather than as problems to be managed. For people facing dementia, these conversations are especially urgent because the disease itself gradually takes away the abilities needed to understand the situation, remember earlier wishes, make plans, and act on them.

I am deeply grateful that Final Exit Network exists and that I found it while I still have the opportunity to think, prepare, talk openly with my family, pray, and make decisions consistent with my values.

Whatever lies ahead, FEN has given me something deeply valuable: people willing to walk beside me as I face one of life's most difficult questions.

For that, I am profoundly thankful.

# Death and Dying in the Media




**-Serene Meshel-Dillman-**
*Take Me Out Feet First*
(Amazon Prime, YouTube, 2026)




This documentary series directed by Serene Meshel-Dillman, and developed in partnership with Compassion & Choices, has now opened a second season. Here, we review all six episodes of season one, of varying length, all dealing with cancer patients exploring the option of Medical Aid in Dying.

The pilot episode (95 minutes) features the director's own parents. Her mother, Miriam Reiner Meshel, used California's End of Life Option Act in 2017 to peacefully end her suffering from a very rare, aggressive cancer. Her father, Robert Meshel, opposed his wife using the option, but later changed his mind. Says Meshel-Dillman, "I'm sharing their story because it shows the courage, determination, and love both my mom and dad embodied in their final days. They taught us that there's grace in being in charge of your own destiny. This law, legal in only ten US states and Washington DC, deserves national endorsement. 'Take Me Out Feet First' is their legacy."

Episode 2 (56 minutes) profiles Illinois native Andrew Flack, who at 34 faced terminal cancer by starting a podcast with his roommate entitled "'The Death With Dignity podcast," in which he chronicled his cancer journey and interviewed many of the people he encountered along the way.

The third episode (34 minutes) profiles Danna Nelson, a 26-year-old trombonist who returned to Minnesota from school in Finland after being diagnosed with a rare childhood cancer, to live with her parents who helped care for her until the end.

Episode 4 (61 minutes) profiles Colorado resident Mimi Ankerholz, a 49-year-old woman with metastatic breast cancer, as she discusses her family relationships and her decision to end her life in an interview conducted two days before she used medical aid in dying.

Episode 5 (47 minutes) profiles Erika Gergerich, PhD, a professor of Medical Social Work in New Mexico diagnosed with stage 4 breast cancer when she was 8-1/2 months pregnant. Already a single mom, Gergerich moved back to be near her family in Arkansas so her parents could help care for her and her new baby. Also profiled is Michigan resident Trisha White, who has stage four metastatic breast cancer. White, the youngest of five siblings all brought up in a religious home, is a staunch atheist who navigates the love and support offered by family and friends while fiercely guarding her independence.

The final, and shortest, episode (21 minutes) features experts in the field of medical aid in dying. Kim Callinan is the president/CEO of Compassion & Choices and Compassion & Choices Action Network. Callinan's grandmother had an advanced directive that was not honored. When she was dying in a hospital she tried to pull her tubes out. Conversely, her grandfather had a beautiful end by his own choice and his family was able to say goodbye. Dan Diaz describes how his wife, Brittany Maynard, felt that "having a good dying process was an extension of having lived a good life." They moved from California to Oregon to use MAID in 2014 before medical aid in dying was legal in California. Kaiser Permanente pharmacist Sue Gess, who has been present at many bedsides, describes the medicine ingestion process for MAID. And lastly California physician Dr. Chandana Banerjee, City of Hope Dean, Director and Designated Institutional Official, Graduate Medical Education, explains, "The dying patient is a person with profound suffering, facing agony. Why would you not want them to have a peaceful end?"

Please consider becoming a subscriber to their YouTube channel (www.youtube.com/@Confiscatedfilm) so more stories on choice in dying can be told.

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**-Eric Beck Rubin-**
*Ten Clear Days*
(Turtle Point Press, 2026)

The protagonist of this short novel is the author's grandmother, born Marianne Manoville, referred to variously as Mary Beck, Patient, MB, "Greni," "Mom," or "Marikám." After a heart attack and stroke, Mary is rushed to the hospital where surgery is successful, and her recovery begins. However, she is adamant that she wants to die. With Canada's newly enacted MAID legislation, she is eligible if she can reiterate her position for "ten clear days."

In ten increasingly fraught chapters on a Tuesday through the following Thursday in August 2018, we follow Mary's limited but determined communication with her uncomprehending family and physicians,

interspersed with documentation of her early life in Hungary, ultimately surviving the Holocaust and moving to Toronto. Rubin, a novelist and academic, uses the experience of his own family as well as his research into the Holocaust to convey in refreshingly unadorned prose a complicated and important portrait of intergenerational family dynamics and medical ethics. Will Mary ultimately achieve her goal?

The relationship between Mary and Eric is, unsurprisingly, particularly poignant. In contrast to the bedridden patient she has become, Rubin lovingly renders the fullness of her life: her suffering, loss, and the devoted family she produced. This lightly fictionalized account of pursuing the right to die offers an illuminatingly intimate perspective into many complex issues.

## -Asunción Álvarez del Río-

*For a Better Ending: Knowing What to Do to Die with Dignity*

(2025; English translation 2026)

"When you hold death in view, life takes on more meaning."

So states Asunción Álvarez del Río, a faculty member of the Universidad Nacional Autónoma de México (UNAM), who has served as president of the World Federation of Right to Die Societies (WFRtDS) since 2021. *For a Better Ending*, first published in Spanish in 2025, has now been ably translated into English by Cristina Palacios de Martinez, allowing an even wider audience to appreciate this personal and compassionate exploration of end-of-life options internationally, with a particular emphasis on Mexico and other Spanish-speaking countries.

He continues, "I'm convinced that we need to engage with death, acknowledge the feelings it stirs up, understand the choices available at the end of life, and learn how to support each other through that final stage. There's more conversation about death today than there used to be, but we still have a long way to go. Too many of us avoid the topic in personal conversations, which means we never build the tools we need, not to just manage the fear and grief it brings, but to find genuine comfort and peace."

Among the many topics sensitively addressed here are the options of minors, people facing a "completed life," mental illness and dementia, the role of advance directives, the impact of COVID-19 on end-of-life choices, Mexico's legal landscape (medically assisted dying is currently prohibited in Mexico), and a plea for additional cases that might help advance medically assisted dying globally. Brief case studies are interspersed to support Álvarez del Río's well-argued points. I was heartened to see Final Exit Network referenced more than once in this global survey.

The book concludes with a moving interview with her friend and co-author of *A Farewell in Harmony* (2015), therapist and thanatologist Elvira Cerón, now herself a patient dealing with an illness that brought her into direct contact with death.

This is an important addition to the growing body of literature advocating for the international right to die. I'll allow Álvarez del Río the last word: "My sincere hope is that this book opens conversations, personal and shared, that help us live lives that make room for death. When the time comes, the goal isn't to fight the inevitable. It's the move toward it with relief and inner peace knowing that the ending of our life's work has been the best it could be."

## -A Million Little Things-

(ABC Network, 2018-2023)

**Spoiler alert:** In the series finale (Season 5, Episode 13, "One Big Thing"), Gary Mendez (James Roday Rodriguez) experiences severe pain and loss of bodily function caused by his terminal recurrence of breast cancer. When it reaches a point where he can no longer speak or eat comfortably, drastically reducing his quality of life, he chooses to hasten his death. This event bookends the series premiere in which a friend's suicide shapes this incredibly close friend group.

Gary's friends Rome and Eddie honor their secret pact to help him die with dignity if his suffering becomes unbearable, and his wife Maggie supports his choice, staying by his side as he passes away peacefully surrounded by the love of his family and friends. This dramatic sequence in a popular television series once again illustrates the normalization of personal choice in end-of-life options.

## -A Film by Steve Brody-

*The Strawberry*

(2026)



On his 80th birthday, Herb Kaplan (Mike Farrell) receives unwanted news from his doctor: His pancreatic cancer has metastasized and is inoperable. Still grieving the protracted death of his beloved wife the previous year, he accepts the news stoically, initially withholding his terminal prognosis from his two adult sons, his daughter-in-law, and his young grandson. Among various treatment options Herb is offered a brochure about death with dignity. This piece of paper becomes an important element in his journey. As the situation becomes clearer, past family wounds and expectations are revealed.

This first feature (a micro-budget indie), directed and edited by brothers Kyle and Carlos Eduardo Plummer, was shot in fifteen days entirely on location in Cambria, CA. The screenplay was written by Cambria clinical psychologist and writer Steve Brody, directly based on his own experience. Star Mike Farrell, now 87, is best known for portraying Captain B.J. Hunnicutt on the iconic TV series M*A*S*H. The film's title is taken from the famous Zen Buddhist parable, "The Tiger and the Strawberry." Despite its measured pacing and overzealous soundtrack, this heartfelt film is to be commended as one of the first features to courageously explore the controversial concept of medical aid in dying. Though not yet picked up for wide distribution, opportunities to view it may be found online at www.thestrawberrymovie.com.

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**OUR MISSION** *To educate and support those who want choice in dying.*

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