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A suicide note, and a frantic search, scar a daughter for life

By Regina

My dad suffered from lung cancer for two years. I was just a teenager at the time. I remember coming home from school every day and listening to him moaning in pain. Within two years, he went from a big, stocky guy to a frail, skinny man who looked 20 years older than his age.

One night, it was 2 or 3 in the morning, I was awakened by my mom's blood-curdling scream. She frantically tried to tell us that my dad had left a suicide note while she was sleeping, and left with the car to kill himself. The suffering was just too much for him to bear.

We were all panic-stricken while trying to figure out how best to find him. My brother called the relatives; another brother took the remaining car to drive around looking for him.

My mom wanted me to walk down the nearby golf course with her to search for him. It was dark and foggy, and she kept asking me to look up at the trees to see if he tried to hang himself.

I was petrified, and I believe this experience really impacted me and my views on death with dignity. The horror of that night has stayed with me for the rest of my life.



Due to the pain and medication he was taking, Dad was driving erratically down the highway, and it caught the attention of a police officer who tried to get him to pull over. But my dad was determined to end his suffering that night.

He saw an overpass and decided to pull over so he could jump from the bridge. He ran as fast as his body would allow, but the officer caught up with him before he could reach the bridge. Mistaken as a criminal, he was pushed down to the ground and handcuffed.

SUICIDE NOTE *continued on page 2*

That is how we found him, all bruised and scratched up, after the police officer finally understood his intentions.

Very sadly, my dad suffered for another few months before passing away.

This whole experience as a youngster made me realize the importance of providing a compassionate choice for those who are terminally ill and suffering horribly, and the tragedy that could result when that choice is not made available to them.

Editor's note: Regina shared her story after FEN requested members to tell their personal end-of-life experiences with difficult (or more-peaceful) deaths.

If you have something to share, or to say why you have endorsed the right-to-die movement, please let us know at ExecutiveDirector@finalexitnetwork.org.



Regina's father, Tao, about 20 years before a slow, painful death in his early 50s.

Wrong author makes no difference

‘Dr. Death’ brings life to book sales

A famous (*infamous*?) right-to-die icon spoke from the grave (kind of) and gave a living RTD icon a big sales boost to a best-selling book, *Final Exit*.

Oscar-winning *Nomadland* (Best Picture, Best Director, Best Actress) includes a passing reference to Derek Humphry's ultimate DIY guide for self-deliverance.



Jack Kevorkian

her seven or eight months to live.

Then she says, “I have this book called *Final Exit* by Dr. Kevorkian. Some people call him Dr. Death. It's like various ways that you can end your life if you need to. It's kind of like a recipe.”

It was a recipe for a run on the book. Suddenly, sales of all versions doubled, then tripled – all due to a surprise mention in *Nomadland*.

The paperback sold out, and Random House reprinted it by July 1.

“It was not pleasing to have the most successful of

my 13 books attributed to someone else,” Humphry mused. “But the reason appears to be that the book's title is better known than my name, while Dr. Kevorkian remains famous for the 130 people he helped to die.” (Kevorkian died in 2011.)

The author error made no difference because the book title name is well known, thus easily found by searchers. “It is rare for any book to be mentioned in a movie, especially a book as controversial as this,” Humphry said.

Final Exit has never stopped selling since it first appeared in 1991.

Back then, Humphry had to publish it himself, under the imprint of the Hemlock Society. To huge surprise, it became a *New York Times* #1 best-seller, remaining on that list for 18 weeks. There were 10 translations.

Sales have continued for 30 years (constantly updated) as paperback, ebook, Kindle and audio – also much pirated – this year after the unexpected publicity boost from a Hollywood blockbuster.

Since the movie's big first screenings, sales are now back to normal. But thanks to some modest Facebook advertising, the *Final Exit 2020* ebook sells all over the world, albeit modestly.

Humphry declined to say if he would give a share of his new royalties to the Kevorkian estate.

Board President Brian Ruder's annual message

Moving ahead (change isn't easy)

It has been two years since I was elected president of the board of your Final Exit Network. The last 12-18 months have been difficult for our Guide program, as we had to slow down our application processing. Our coordinators continued providing information to callers and our Senior Guides continued to support their existing clients, but we were only able to take a few new clients who did not require our air travel.

We are happy to again be accepting new applications.

From an organizational perspective, we have made several changes. The board hired our first executive director, Mary Ewert, and first director of client services, Lowrey Brown, to make FEN more sustainable.

Mary has transitioned FEN to a new financial system in preparation for our first external audit. She participated with a board committee to develop a three-year strategic plan that focuses on how FEN can become more professional and accepted in the right-to-die movement, while being true to our mission and keeping FEN and our clients safe.

She also oversaw development of our new website, which is clear about who we are and what we do. And Lowrey oversaw her first successful two-day training program, to add more exceptional volunteers to our Guide program.

□ The board also launched the Supplemental Advance Directive for Dementia Care (SADD) initiative to allow members with dementia a second option to manage their end days. We provide free legal support for our SADD if that becomes necessary.

□ We also started our Surrogate Consultant Initiative to provide members with advice and

The board is unanimous in its belief that our move toward a more professional organization will attract new supporters and clients ...

support for their AD surrogates.

□ FEN completed the first phase of research with our clients to better understand their psychosocial reasons for hastening their death.

This research will help us improve our services and messaging and may open new areas of research in dying and death.

□ We have also completed a thorough review of how we govern ourselves, to bring our by-laws and procedures up to date.

□ Our magazine has grown to include more stories of clients and their family experiences with people who have chosen to hasten their deaths. That quarterly publication is one of our most

important marketing tools. Please share your copy with friends and neighbors.

These changes don't come without cost. Some older volunteers didn't like the changes and decided it was time to move on. *FEN owes much to these dedicated people, and we thank them for their years of service.*

The board is unanimous in its belief that our move toward a more professional organization will attract new supporters and clients for Final Exit Network and expand our opportunity to play an important role in the right-to-die movement.

Finally, I want to thank everyone for their continued support. We know you have many options for your donations, and *we all truly appreciate your ongoing generosity and support.*

Brian Ruder



Whose pain is it anyway?

– *We have a right to demand treatment for it* –

FROM EXECUTIVE DIRECTOR MARY EWERT



“Dying shouldn’t have to hurt.”

So ended a recent article on pain control at the end of life. The story observes that although the pain of more than 90 percent of all dying patients could be relieved, more than half of those with terminal cancer suffer from poorly managed pain.

Access to good hospice care remediates the situation for some. But no one should be required to suffer through pain before accessing appropriate, sufficient treatment.

Each of us owns our pain, and we have a right to demand treatment for it.

Surveys of patients living in jurisdictions where MAiD is legal

indicate that pain is just one of several reasons they seek to use MAiD laws. But it is an important reason for some, like Regina’s father in our cover story.

Although everyone deals with pain differently, anxiety and pain can create a vicious cycle as patients worry about getting pain relief, and that anxiety may increase their sensitivity to pain.

Seeing loved ones die in pain instills fear in us that our pain, and the pain of other loved ones when approaching death, will be ignored or untreated. Perhaps the worst impact, though, is the lasting guilt by family members who were unable to ease their loved one’s passing, despite their best efforts.

Grief may abate long before the feeling of having failed wanes.

The public battle to curb opioid abuse, while important, raises concerns about providers’ ability to ensure adequate pain management for patients. The American Society of Clinical Oncology, while recognizing the public health concerns around misuse

of prescription drugs, reaffirms the need to ensure access to appropriate pain management for cancer patients.

It’s important that prescription limits don’t prevent providers who treat cancer pain from prescribing controlled drugs at very high doses. It is crucial for patients and caregivers to understand the importance of monitoring pain to avoid relentless breakthrough pain.

If medications aren’t working, the patient or their

surrogate should make that known and request a change in treatment. If those requests fall on deaf ears, FEN Surrogate Consultant Althea

Halchuck stands ready to

provide assistance to FEN members.

She provides information about patients’ rights, as well as ways that surrogates can compel providers to acknowledge those rights. (Althea can be reached at fensurrogate@gmail.com.)

In the spring issue, I invited readers to share their stories about deaths they have observed. Many of you stepped forward, and some of your experiences, including Regina’s, appear in this issue. [Other tragic circumstances sometimes make the news, like the case of [Tennessee teen Dylan Lawrence](#). He died June 25 in a way no one should have to exit.]

I enjoy our enlightening, interactive conversation. I hope you will continue to send me your stories and ideas. You can reach me at ExecutiveDirector@finalexitnetwork.org.

Your support for FEN and the aid-in-dying cause is much appreciated.





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

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VISION

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

MISSION

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

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– Some FEN Partners –

Final Exit Network is partnering with a growing number of organizations dedicated to advancing end-of-life issues, discussions, and the right to choose how we die.



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He was opposed, then supportive – *and then inspired*

Her exit made Mom heroic to him

By Stephen Thompson, FEN Member

It was five years in May since my mother used FEN to help her leave. It's taken me this long to feel okay about sharing our adventure.

On a regular, random Saturday, she said, "Sit down, I have something I need to tell you." I thought she had cancer. She said, "I have decided to take my own life. I've been doing research online about assisted suicide and found this place called Final Exit. I have sent them my medical records and am just waiting for the approval."

I told her absolutely not. If she wanted to go through with this idea, I would not support her. She would have to tell me goodbye and then have Peter, her husband, call and tell me it was over.

Mom had Parkinson's, fibromyalgia, and a list of other issues. She had a constant tremor in her hand and suffered debilitating pain.

She looked at me with moist eyes and said, "Do you really want me to go on living like this" – her hands shaking, becoming unable to walk or feed herself? She said, "I can't paint anymore. I can't draw or make quilts. I am no longer able to write or email. I'm becoming trapped inside this body that is in constant pain.

"I refuse to be held hostage by this disease or by the medical community just waiting to die. I refuse to become a burden on you, Ronnie, or Peter."

I felt trapped in a corner. No, I didn't want her to go on living like that, but I didn't want her to leave,

From that point, the world seemed to be different. I couldn't talk about what I was going through with anyone; I had never felt so isolated.



Son Stephen with his mother, Pat, in healthy times.

either. I told her I could not support her decision. I hugged her neck, and my husband and I left.

We didn't say a word on the drive back to our house. Stunned silence. Quiet disbelief. Those minutes on the drive home would be the beginning of a four-month adventure that still seems surreal.

By the time we got home, I had changed my mind. I called and told her I would support whatever decision she made. I told her, if she was doing it to not be a burden, I could not support her decision, but her decision to end the pain and suffering was probably the most noble thing I had ever witnessed.

Whatever she needed me to do, I would do it with enthusiasm. From that point, the world seemed to be

different. I couldn't talk about what I was going through with anyone; I had never felt so isolated.

Mom said someone from FEN would call to talk with me. The next

day, my phone rang and it was FEN. She told me who she was, made sure she had the right person, and we talked for over an hour. Then she said, "Your mother's death day is May 25."

Out of all we were going through, everything we were trying to come to terms with, those seven words were the hardest to hear. It still rings in my head like an echo through a dark canyon. You will never be prepared to hear those words.

My mother asked me to move in with them, and I did. We had three months left, and she said, "I want us

to be a family one more time before I leave.”

It was three months of tears and laughter. It was an emotional roller-coaster that I could have missed had I not been there for her. Now, I wouldn’t have missed it for the world.

She has twin granddaughters in Florida. I called and told them they needed to come say goodbye. “Why, what happened,” they asked. “Is she worse? Is she in the hospital? Why is it time to say goodbye?”

A thousand questions, and I had to hold the truth. I bought them airline tickets for the next weekend. They flew up and we all had a nice visit. As I was driving them back to the airport, they said, “Uncle Steve, you’re overreacting. She doesn’t seem any worse. Why did you make us come up here?”

Silence. I couldn’t tell them.

But I had an awesome idea! Both my nieces make quilts, like my mom. I asked them to make a quilt of her favorite articles of clothing. So, Mom and I went through her closet, picked out clothes that she liked and shipped them to the twins. I insisted it be made quickly, and they couldn’t understand why. I thought it would be something special for Peter to have once she was gone.

They mailed the quilt with one week remaining. She gave it to Peter, and it was powerful. He placed it on the back of the couch, and it’s still there. I walk by it when I visit him and have memories of those clothes in that quilt.

I left her house on May 24 so she and Peter could have the last night alone. She and I had breakfast the next morning. When the angel from FEN arrived, I left. We agreed that she and Peter be alone to say goodbye.

Mom walked me to the door, obviously in pain. I said, “I love you to the moon and back, forever.” She giggled and said, “That’s a really long way.”

We hugged and she said, “You’ll always be my little boy blue. Son, I hope you know that I love you and that you’ve always mattered to me.”

I turned and walked out the door. It was over. I’ve never cried so hard in my life. About an hour later, Peter called and told me it really was over, and he had called the police. They were on their way and might

want to speak with me, but nothing came of it.

I make it a point not to see people in their caskets. I never have wanted that image of them lying there burned into my memory. I walked into the chapel accidentally as Peter was saying goodbye. I almost bolted, but I saw her hands, perfectly still. No more tremors, no more pained expression – she looked at peace for the first time in years. I touched her hand and told her, “Thank you; you done good.”

The funeral director told me the casket she paid for 20 years ago was no longer available. There was a price difference, and I owed money. I asked, “How much?”

He said, “\$12.”

I laughed out loud and said, “Thanks Mom!”

I’m sorry if this is too long or wordy. She was amazing, and I’m grateful for the opportunity to say goodbye. We had time to make amends and talk about things long-buried that I never thought would come up again.

Having the opportunity that FEN provided my family gave me a new understanding of how temporary all of this really is and to not take one moment for granted. I can honestly say this adventure changed me.

The day after her funeral, I woke up around 3 a.m. At the hotel, in the small town where she was buried, I took

my dog outside to use the bathroom. It was pitch black, hot and balmy, like only Southern nights can be.

I turned on my phone and saw a Facebook post from someone I didn’t know. “Proverbs 31:25” was all it said. We are not religious, but I knew Proverbs was from the Bible, so I Googled it: “She is clothed with strength and dignity; she can laugh at the days to come.”

A chill went down my spine and a feeling of calm washed over me. I knew she had figured out a way to let me know she was okay. Another surreal moment in this adventure.

It doesn’t matter if anyone ever reads this. Mom, I hope you know how proud I am of you. You will always be my hero for doing what you did. A hero without a cape. An inspiration I am unable to share. I’m very, very proud to have been your son.



Stephen’s parents, Peter and Pat Thompson.



Assisted death is alive and well (at least in fiction)

By Jim Van Buskirk, FEN Member

Assisted death seems to have (re)entered the current Zeitgeist, at least in my recent cultural expeditions.

By no means comprehensive, here's a list of what I've been reading, viewing and/or hearing about. I'd love to hear what you have uncovered that I might have missed.



- Belinda Bauer's latest crime novel *Exit* follows a lonely widower who volunteers with the Exiteers, a right-to-die group whose members assist the terminally ill.

The families of those ailing give permission to Exiteers to witness the self-administering of nitrous oxide through a mask, ensuring a peaceful death. An unintentional mistake sends an Exiteer into hiding from the police as a murder suspect, and the victim's family looks for answers.

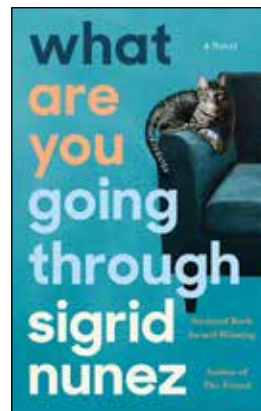
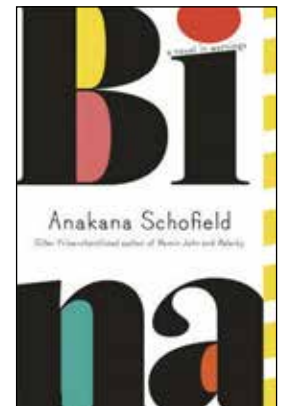
The details are so similar, it's as if Final Exit Network has been transplanted to Bideford, England.

- The protagonist of Karolina Waclawiak's recent novel, *Life Events*, is a 37-year-old woman, on the verge of divorce and anxiously dreading the death of everyone she loves, who deals with her existential crisis by enrolling in the training course offered by a collective of "exit guides." There she learns to provide

companionship and a final exit for terminally ill patients seeking a conscious departure.

- And then there's Anakana Schofield's *Bina: A Novel in Warnings*. Although indescribably elusive, elliptical, and experimental, the Irish narrator has (apparently) become implicated in her close friend's hastened death.

The author's acknowledgments include this shout out: "To all those brave souls who fought tough legal cases that led to the MAiD program in Canada."



- Sigrid Nunez has dealt with planned death in two recent novels: *The Friend* (2018) and *What Are You Going Through* (2020).

In the latter, an unnamed narrator is sequestered in a New England Airbnb with a terminally ill friend who's preparing to end her own life. Nunez's self-referential prose is

vague about terminology and details, but in interviews she makes a distinction between suicide and euthanasia. She quotes friends (plural) telling her calmly, “It might be when I’m 80, but this is how I think my life will end.”

- ***Supernova*** (2020) stars Colin Firth and Stanley Tucci as a long-time couple dealing with Tucci’s character’s cognitive decline. They travel together, visiting family and friends, as he explores options to determine the time and method of his own death.

“I want to be remembered for who I was, but not for who I’m about to become. That’s the only thing I can control,” he poignantly informs his not-yet-accepting partner.

- The title of Ruben Grijalva’s new play, ***Shoot Me When....***, says it all.

According to the *San Francisco Examiner* review of a recent production, the protagonist is in “what appears to be an early middle stage of dementia, the stage where strangers can’t tell there’s anything wrong, the stage where she still remembers most but not all things and can fly off the handle unexpectedly. The stage where, to her children, she often seems like her old self, craving ice cream and Manhattans, laughing over a family joke about ‘cauliflower pie,’ using the same old familiar expressions, her favorite being a wry ‘Just shoot me when...’”

Not having seen it, I can’t tell you how it ends.

- In ***Mary Kills People***, the Canadian television series which began in 2017, Caroline Dhavernas stars as Dr. Mary Harris, working at the emergency department of the community’s General Hospital.

She also has an illicit side business as an end-of-life counselor: She and a partner provide assisted suicide in the form of a pentobarbital-and-champagne cocktail, as a compassionate alternative to death tourism to Switzerland. Things get complicated when the police start investigating them. Of course.

A few older cinematic examples were brought to my attention by my friend the Rev. Elder Jim Mitulski, who witnessed many assisted deaths throughout the AIDS pandemic.

- In ***Harold and Maude*** (1971), Bud Cort is horrified when Ruth Gordon reveals that,



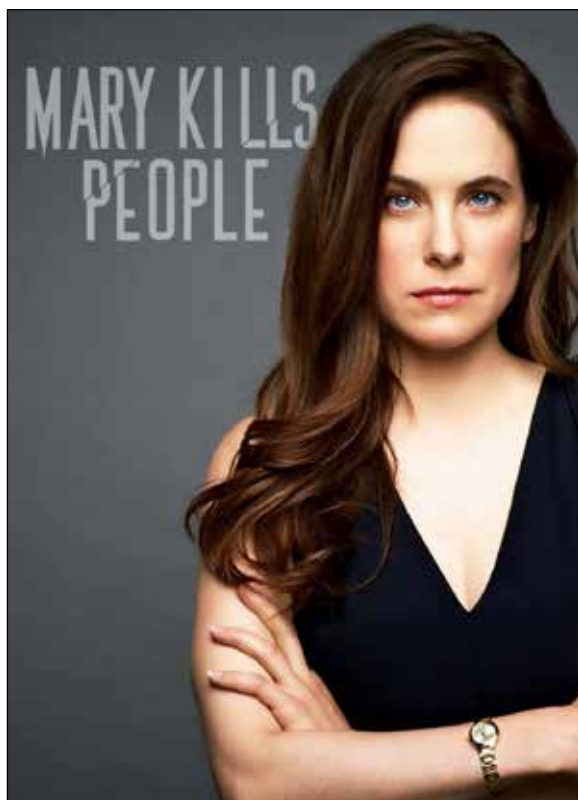
as planned, having turned 80, she has taken a pill to end her life.

- In ***Fried Green Tomatoes*** (1991), when Mary-Louise Parker’s character is dying of cancer, her best friend Mary Stuart Masterson’s character is shown

wordlessly lifting a syringe and tapping it to remove an air bubble, before administering it, putting her to sleep.

- The plot of ***It’s My Party*** (1996) was based on Harry Stein, an accomplished architect and designer, the ex-lover of Randal Kleiser, the film’s director. Having been diagnosed with AIDS-related progressive multifocal leukoencephalopathy, the protagonist hosts a party for his family and friends, at the end of which he will commit suicide by taking Seconal.

Many more titles are out there, and many more are likely to come.



*The vision that we might
'go together' has seemed a
promise and a crescendo.*

*From Tom & Mary Torinus
To our family and friends – January 8, 2021*

Faced with ever-greater losses of mental capacity and increasing suffering and pain, Mary and I have decided individually and together to end our lives. To “go together” as one heart, one soul, one love.

On Thursday, Jan. 7 (2021), we hastened our deaths. By our choice, we died gently and peacefully while holding hands and lying side-by-side in our bed at home.

For us, it was the culmination of our 55-plus years of love and life together in which we had become one life, one heart, one soul. A grand finale for our lives lived fully together, our cup running over.

We emphasize that we see this also as the beginning of a new life together, one which we cannot define, but which we know in our heart of hearts to be a life of new freedom, innocence, beauty, love and peace. So begins our new grand adventure.

Mary was diagnosed with dementia in early summer of 2020. We had suspected its presence in her for several years. We intentionally delayed a medical diagnosis because there seemed no cure beyond what we were already doing, and because we knew the definitive diagnosis would only give us more fear and dread. Her symptoms have steadily worsened, especially since summer.

I was diagnosed with rheumatoid arthritis over 10 years ago. For years before, I could find no diagnosis for my joint pain in neck, shoulders, back, wrists, and knees. Finally, I found one and have had excellent medical care since. Yet, for me, the chronic pain has been challenging indeed and has had a cumulative effect, slowly stealing away the zest, passion, and wild desire for life that I have

EXIT

A Wisconsin couple



Mary and Tom Torinus loved Lake Michigan and any waterfront – but not

loved in myself and hope you have known in me.

I still experience much pain. I have long been dependent on opioids and other drugs for any sense of well being. I must use more and more of these drugs just to get through the day and night.

These are not complaints. Hardly so. Mary and I have long celebrated our lives and have been filled with gratitude for our life together with all of you all these years. The vision that we might “go together” has seemed a promise and a crescendo.

We have approached our death just as we have tried to live each day: with an ever wider and deeper appreciation of the beauty all around us, with an ever greater sense of the sacredness of our lives and yours, with profound reverence for all persons and creatures and moments, and for creation itself.

With deepest discernment and personal authenticity, we feel we have been called to this graceful ending together. At age 82, we share a sense of wholeness and

RIGHT

le's *Love Story*



t nearly as much as they adored each other.

completion which younger people cannot yet grasp. This fullness slowly and generously has come upon us and has offered this right time.

We are deeply certain that this ending also is a new beginning for us, a transformation into a life even more expansive and beautiful. Nothing will be lost; all will be gained. We look forward to a more relaxing and profound, if inexplicable intimacy with each other, with this world and with you.

Everywhere in nature, life and death are so intimately intertwined. In the dark underground, a seed husk breaks open into a shoot, then reaches itself upward to find the light and warmth of the sun; this forms a stem, then stalk or trunk, then branch, then twig, then leaf, then fruit, then new seed. The seed drops into soil made rich and nurturing from the past lives of other fruit and trees and leaves. It becomes soil, which now nurtures new life.

In all of this, there is a vibrant life and a beauty, even glory. Mary and I now become the soil life grows in –

Summer 2021

*We are deeply certain
that this ending also is
a new beginning for us.*

maybe a new seed.

Here is a favorite quote of ours from Wendell Berry's *The Autobiography of Jaber Crow*:

I was all filled to running over with the thought of heaven. I thought an unimaginable thought of something I could almost imagine, a sound I could not imagine but could almost hear: the outcry when a soul shakes off death at last and comes into heaven. I don't speak of this because I "know" it. What I know is that shout of limitless joy, love unbound at last, our only native tongue.

None of us can see beyond death with our five senses and rational/logical minds. That limitation allows us to hold any imagination we want about our next lives. Mary and I have chosen the best imagination, the one that has best enhanced our lives in these bodies on this Earth.

Why not?

In a very real way, though, this vision is far more profound than an act of imagination. It arises from all of our human experience and the deepest source of our knowing.

There are those who will feel we have made a choice only God should make, that God should take us "naturally." Our experience is that God has always come to know us more intimately through our conscious growing and has become ever more present in us as we have taken conscious responsibility for our lives.

God also has guided our conscious choice in this final act. It is a calling.

Medical technology has made our lives longer and more joyful. It is also used in the medical system in usual but unspoken ways to hasten the deaths of those who are suffering greatly with no hope of lucid recovery.

Our God cannot wait to see us, hold us to her breast. "I have only one question," she will ask urgently, "Have

*It is very difficult for us humans ...
to accomplish a conscious, gentle,
compassionate death, the kind
we give to our beloved pets.*

you enjoyed the gift life I gave you?” We will say, “Yes.”

We are aware that our “going together” will shock many people. Others may be grateful to know that this is possible.

We have examined closely all alternative paths forward, always with a great depth of feeling and bold openness, ranging from gripping fear, to deadening sadness, to childlike wonder and hope.

Mary cared for her mother as she suffered dementia for 10 years and for her sister, Stephanie, as she suffered dementia for as many years. Her mother spent a full decade at home, the last year-and-a-half with a full-time, 24/7 team of six caregivers. Stevie spent seven years in nursing facilities. Both lost almost complete mental capacity.

As Mary cared for them through those years, she determined that if she were struck with dementia, she did not want to live out the full ravages of the disease, losing her sense of herself, her loved ones, her life. Also, she was determined not to go into an institutional nursing facility. Of these things, she has been most certain to the end.

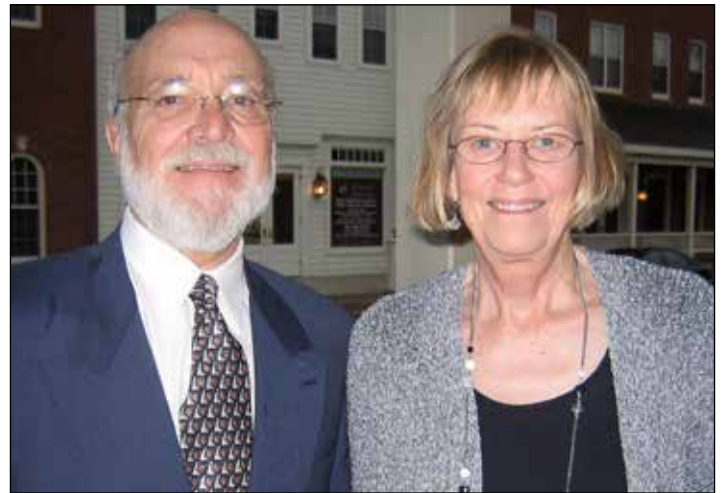
Knowing that his own rheumatoid arthritis, osteoarthritis, spinal stenosis and sleep apnea would not be terminal but would bring chronic, long-term pain and suffering, Tom has for five years studied methods of dying with dignity by conscious choice when his suffering became unbearable.

Medicines, the people who developed them, and those passionate medical doctors, nurses, and practitioners who have cared for us immensely extended our lives and capacity to enjoy it. *Bless them all.*

Yet the time did come.

It is very difficult for us humans, in the culture we have created, to accomplish a conscious, gentle, compassionate death, the kind we give to our beloved pets. Mary and I are pleased to have found great help from passionate, compassionate and courageous people who have stood strongly for a culture and a legal structure which would allow persons to choose their own time and way of dying and get medical and personal assistance in carrying out their desires.

These people see this as the next civil right, as we do ... We see them as the new suffragettes ... If we were



younger, we would join the movement to allow and assist people to die consciously with dignity.

This “going together” has been an extremely challenging path for our family. Few long-time partners even allow themselves to consider it, even though it might feel a wonderful culmination of their love.

Our daughters, Alex and Liz, have been in full dialogue with us at every step of the journey, sharing all of our thoughts, wonderings, overwhelming feelings, spiritual questioning, and questing. We decided that we would move forward only step-by-step as one, and only in the spirit of love rather than fear.

We would take no step until all of us were together, One, acting in Love. This process has demanded immense courage and trust in God. It has also grown us deeply as a family.

From all of you, our family and friends, we ask understanding, empathy, compassion. As Atticus Finch advised to Jem and Scout in *To Kill a Mockingbird*, we hope you will “walk awhile in our shoes.” From some, perhaps, we will even need forgiveness. We humbly ask for that, too.

You have played such an inextricable role in our beautiful love story, which can only be a story of relationships. “Thank you” is the most we can possibly say and it must suffice. We hope we have been a gift of love to you as you have to us.

With you forever,

Mary Tom

Editor’s note: To learn more about these remarkable people, read the [obituary for Tom Torinus](#) and the [obit for his wife, Mary](#). Their daughters, Elizabeth and Alexandra, agreed that their parents’ dying statement, their undying love, and end-of-life plan are things they would have shared with anyone.

Speakers keep Zooming ahead; FEN hosts 1st webinar

By Janis Landis, FEN Board Member

COVID restrictions have largely eased across the country, but some things learned during the pandemic were too positive to ignore or forget.

Meeting via Zoom has unexpectedly become a lifeline for many of us this past year. It's how we've kept in touch with family, friends, doctors, etc. Speaking for myself, I went from never having heard of Zoom to being able to choose "gallery" or "speaker view" in a very short time.

For FEN, needing to maximize efficient ways to reach the public, it has become a game-changer. I recently provided a presentation to a retirement group in New Hampshire. Going there in person would have meant at least two days of travel, hotel, and meals.

But with Zoom, I spent no time and money on the road. I was able to see the participants and talk with them just as I would in person. And when I clicked off, I was home!

Melanie Raine, our speakers bureau coordinator, ensures that attendees get e-copies of our FEN magazine (another savings over printing extra copies).

This online technology seemed the perfect way to supplement our outreach to FEN members with focused presentations. The expert assistance of a Zoom specialist, Bryleigh Raethel, brought us up to speed on the professional "dos and don'ts" of a webinar.

And so, after a trial run with a small group of FEN members, we were ready to go nationwide. We invited all members on April 17 to join us on Zoom.

Executive Director Mary Ewert served as moderator and fielded questions. Three panelists spoke on important topics:

- FEN Surrogate Consultant Althea Halchuck explained her role and gave tips for choosing a surrogate, and for serving as one.
- Robert Rivas, FEN attorney, discussed our Supplemental Advance Directive for Dementia Care (SADD). He explained how FEN hopes to use SADD to provide test cases that will broaden the rights of

dementia patients to have their instructions honored.

- Crystal Cannon Flores, a death doula, discussed Voluntarily Stopping Eating and Drinking (VSED). She walked us through what a VSED death entails, using an actual case she oversaw through her organization, [The Grateful Death](#).®

The Q&A session reflected the keen interest and knowledge of not only our speakers, but also of our members.

We see many opportunities ahead to continue to educate and learn from our wonderful FEN community, which grew recently through our participation in the annual general assembly of the Unitarian Universalist Association (UUA).

That "virtual" event was held entirely online June 24-27, where FEN had a "booth" that was visited 578 times. FEN Outreach Coordinator Gary Wederspahn organized our presence and reports that our 14-minute introductory video was viewed 71 times.

In addition, we had 48 requests for trial FEN memberships and/or inquiries about the speakers bureau. Gary networked beyond our booth and got 27 additional leads for possible speaking engagements.

"In-person presentations may resume on a local basis, where a speaker is in the best position to assess conditions in their own community," said Gary. "Still, there is significant risk in some COVID hot spots where we expect to get requests. In those cases, we will encourage and remain focused on Zoom programs."

Althea and I are available to present in-person to retirement communities and aging-in-place groups, but we've found that the Zoom format is better-suited for these audiences. Participants need not travel or even be physically mobile. We can come into their residence via laptop, tablet, or smartphone.

How efficient is that?



Janis Landis

***FEN had a 'booth' that was visited 578 times
(and) our 14-minute introductory video
was viewed 71 times.***

A hospice RN was pushed to the brink – *what does that say about your chances?*

‘Sleep deprivation amplified every emotion and wore me down quickly.’

By Helen Bauer, RN BSN CHPN

My surrogate story started like so many others. A worrisome phone call about a sick friend in the emergency room. In the car, on the way to the hospital, I reviewed the packet of papers she had given to us several years before.

Durable Power of Attorney – both my husband and me. Medical Power of Attorney – me. No alternate agent, just me.

I was startled to read this and even more concerned to find our friend, Betty, incoherent from sepsis when we arrived at the hospital. Betty had been a part of my husband’s family for over 30 years, one of those “honorary aunts” who had been with us for all the birthday parties and holiday celebrations.

She and I had always been friendly, but had never had serious conversations about dying or end-of-life wishes.

Betty had been undergoing treatment for cancer. She wasn’t responding well, and had recently been residing in a rehab facility. The goal was strengthening, to enable her to return to living independently in her own home.

***I did the only thing I could think to do:
I kicked into nurse mode.***

There were reports of depression, unwillingness to participate in her therapy regimen, and withdrawal from interacting with friends who would come to visit. An infection had gotten out of control, and her blood sugars were off the charts.

I did the only thing I could think to do: I kicked into nurse mode. Speaking with the hospital staff gave me a pretty good understanding of Betty’s immediate medical needs. She was admitted into ICU to receive close monitoring and IV antibiotics. Even with all the treatment, her condition deteriorated.

They told me she was dying. “Moribund” was the word the doctor used. Even he couldn’t have a helpful discussion with me about my new-found caregiving responsibilities.

MY SURROGATE STORY

Thank goodness for my hospice training. When I mentioned the possibility of hospice care, the doctor immediately gave his stamp of approval and signed off. I sat with the hospice rep, signing papers to elect hospice care on Betty’s behalf. The whole situation was a scramble to understand her condition and determine precisely for what I was responsible.

It was evident that Betty could no longer make

***I found myself short-tempered
and exhausted after about a week.***

***I was sad about Betty’s condition,
knowing it was critical.***

The emotion I did not expect was anger.

any decisions. When she was alert enough to speak with me, she asked for her mother, who had died years ago. It was heartbreaking to hear.

One of the biggest blessings of this unexpected caregiving situation was the inpatient hospice facility. Betty was placed there for a short-term stay, still very confused and unable to help me make decisions.

Along with several of her friends, my husband and I went on a scavenger hunt for vital items I needed to pay her bills, talk with her insurance company, and consult with someone at the bank.

Because Betty had no close family, I was charged with making funeral arrangements. Her distant cousin went with me, but neither of us had ever heard Betty discuss any end-of-life wishes. We were flying blind as we made decision after decision, all based on what we knew about how Betty had lived her life.

I found myself short-tempered and exhausted after about a week. I was sad about Betty’s condition, knowing it was critical. The additional emotion I did not expect was anger.

I was so mad that she had put me in this position! How could Betty expect me to make good decisions for her when she never told me what she wanted? Where did she want to live her

“We were flying blind as we made decision after decision.”

last days? Was there any money for a caregiving system? Yes, she had a plot at the cemetery where her parents were buried, but how was a funeral supposed to look?

Guilt also overwhelmed me. What kind of hospice nurse was I that Betty never felt comfortable enough to talk with me about these all-important decisions?

I know from years of experience that the aggravation of my surrogate role could have been avoided.

Sleep deprivation amplified every emotion and wore me down quickly.

As a hospice nurse, I know from years of experience that the aggravation of my surrogate role could have been avoided. If Betty had sat down with me and had conversations (not just one, because that never gets it all done) about her advance care plans, things would have been different. I would have listened. We would have been equipped to provide the type of care she deserved and wanted to have.

We placed Betty in a personal-care home with a warm, loving environment. She was surrounded by items from her home she could recognize. She received loving attention from the small staff.

When her condition declined and death was imminent, they took Betty back to the hospice facility. My husband was with her the night she died, playing Sinatra softly for her as she transitioned out of this life. It was what hospice professionals call a good death, one that was comfortable and peaceful.

I'm grateful for my experience with Betty, honored that she trusted me to make such personal decisions for her when she was most vulnerable. I do realize, however, that my surrogate story is a cautionary tale. Without my hospice training and connections in the caregiving community, we would have been floundering as we tried to determine how best to care



Photo by Rachel Lynn Photography

Helen Bauer

of [The Heart of Hospice](#), a group of projects designed to educate, encourage, and support anyone who needs information about end-of-life care. Its mission is to enhance the hospice experience for patients, caregivers, volunteers, and hospice professionals.



for my friend.

Having no Advance Directives or discussions complicates end-of-life care. It's easy to make mistakes; provide unwanted, unnecessary, and expensive medical attention.

Betty is buried very close to her parents. She always liked yellow roses, so we placed them on her casket. Her close group of retired teacher friends gathered to grieve. The eulogy described her love for her dog, a years-long devotion to teaching, and a passion for travel.

While Betty never told me what she wanted for her funeral, we made it all about her – intimate, warm, and friendly; remembering Betty in the best way possible.

Editor's note: The author is a certified hospice and palliative nurse currently working as a hospice consultant and founder

Where there's a will, there's a way

The gifts that members and friends bequeath to Final Exit Network upon death typically account for more than half of every dollar of FEN's budget.

Please remember us in your will, or name FEN as a beneficiary in your IRA or other financial product. It is easy to do and requires no legal advice. All you need is our tax ID (80-0119137) and address: Final Exit Network, POB 10071, Tallahassee, FL 32302.

If you have any questions, we'll be happy to answer them – just call us toll-free at 866-654-9156. We'll help you through the easy process to leave a gift for FEN.



Quality of life is much more important than quantity of life. I have and will continue to accept many of the limitations that aging brings, but I will not accept debilitating dementia.

What's ahead?

The cloud of dementia, and his wife's horrid death, prompted Roger to join FEN

By Roger Ignatius, FEN Member

I was diagnosed with Mild Cognitive Impairment (MCI) and had memory problems for many years, most likely 20-plus, but I can't remember exactly. By that, I mean difficulty remembering what I've read, watch on TV, what I've said in conversations, and who I've spoken to. It was one of the factors that led me to retire when I was 54 back in 2005.

My wife Jeanne began having cognitive problems in 2009 after knee surgery. She started having difficulty shifting her weight onto her operated leg. Instead of shifting weight over, she would lean her head in that direction. Then came a bout of dehydration, respiratory infection, and incoherence that landed her in the ER where the doctor reviewed her head CT and said, "Her

brain is older than her age."

Three years later, a robust work-up diagnosed my wife with early onset dementia. For several years, she didn't want to know where her disease was heading, but I needed to know to be a better care provider. We began using senior services and adult day care to support her needs. We connected with the local Alzheimer's association, attended seminars, support groups, and functions to make the most of a crappy situation.

In December 2015, I had intense pain in the upper abdomen, but I couldn't go to the ER because I was home caring for Jeanne. My pain increased over the next months and led me to place her in an assisted-living facility. Toward the end of 2016, Jeanne became much more unsteady in her walking. She fell twice in

2016 resulting in one ER visit after hitting her head. In January to mid-June of 2017, she totaled six falls with five ER visits and two hospitalizations.

The second one was for “altered mental status,” where Jeanne would scream and move her legs, but couldn’t explain what she was experiencing.

I had been trying to get her into palliative or geriatric care for years, but Kaiser would reject my requests since she was not 65. I happened to find a hospice eligibility chart and learned that her weight loss was a qualifier when accompanied by dementia. That finally got her into hospice on June 14, 2017.

On July 14, my gall bladder was removed after finally determining that was the cause of my abdominal pain. Jeanne, now non-ambulatory, still managed to fall out of bed and hit her head.

Jeanne deteriorated until she died on July 23, 2017.

Several times over the last months of her life, I’d ask if I could find a way, would she want to end this dementia journey? She said no. I did my best to honor her desire, not wishing to know where this was heading. However, that led me to buy *Final Exit*.

I attended Alzheimer’s and grief support groups even after Jeanne died. I did this both to help myself heal as well as to share what I could with folks who were still in their caregiving role.

I also stressed that they need to have a structured plan, since the dementia journey is very unpredictable. What will happen if something happens to them? Who will take care of their loved ones?

With Jeanne gone, my MCI diagnosis prompted my call to FEN. I requested documentation from the neurologist about my diagnosis, which I provided to FEN along with my letter of intent, and I’ve been a lifetime member ever since. (I try to contribute to your great cause as often as I can, and you are my Amazon Smile designated charity.)

There is no way I will ride out this disease like my wife of almost 44 years did. Nor do I want to subject my children to the demands and stresses of caring for someone with dementia or who is in chronic pain.

Quality of life is much more important than quantity of life.

I have and will continue to accept many of the limitations that aging brings, but I will not accept debilitating dementia if that turns out to be my future.

The issue is not financial for me, but rather a dignity and quality-of-life consideration. I have stated for many years that we treat our pets much better than we do ourselves when it comes to end-of-life compassion.

Jeanne and I have two children. Our daughter is married, and I now have both a beautiful and wonderful granddaughter and grandson who live about five miles away. They all participated in discussions and decisions about Jeanne as her dementia progressed, as did several of my and Jeanne’s siblings.

Even when Jeanne didn’t want to inform our kids or our families about her diagnosis, I kept them in the loop. I’ve done the same with my diagnosis.

I’ve told my children I will not ride out dementia if it progresses, and they know I belong to Final Exit Network. I reinforce this from time to time, as well as during the year-end family discussions I hold to discuss my financial situation, where important documents are, etc.

And I’ve had my elder-law attorney add an addendum to my Advanced Directive that documents and elaborates on my wishes for care in

case of dementia or other progressive diseases, and that includes VSED (Voluntarily Stopping Eating & Drinking).

What I want from Final Exit Network is assistance in helping me prepare to end my life, if and when dementia progresses or some other “trigger event” occurs. I need to do all preparation and perform the steps while I am still able to do it myself. FEN has provided that information and support over the years, and I feel I am ready when the time comes.

I must be able to procure and assemble devices and follow directions – *or my window of opportunity will close*, and I definitely don’t want that to happen!



Jeanne and Roger Ignatius



FREE SPEECH

FEN faces another Minnesota case over the right to simply give advice – and no one even says what crime was committed

On Friday, July 16, Minnesota authorities filed a motion urging the U.S. District Court to toss out a lawsuit filed by Final Exit Network and two of its Exit Guides to strike down a one-of-a-kind law making it a crime to give instructions on how to accomplish a painless, dignified self-deliverance.

FEN and Exit Guides Edmund (“Ted”) Ballou and Kevin T. Bradley have a due date of Aug. 6 to file a brief in opposition to Anoka County’s Motion to Dismiss their lawsuit.

A hearing is scheduled to take place November 17 before U.S. District Judge Nancy E. Brasel in St. Paul. She would likely rule in a month or two.

FEN, Ballou, and Bradley filed the federal court lawsuit against the Anoka County Attorney, who in Minnesota is the county prosecutor, and the sheriff of Anoka County. FEN, Ballou, and Bradley – who is also a FEN board member – are each represented by separate attorneys.

Ballou and Bradley encountered Anoka County deputies on May 4 in Columbia Heights, a northern Minneapolis suburb. They had just arrived at the home of an Exit Guide Program client for a meeting when deputies arrived seconds later.

It turned out that an unidentified “family acquaintance” had called the local police. The deputies seized Ballou’s backpack and Bradley’s travel bag before ordering them to leave.

At press time, the sheriff’s office had still refused to return the bags and their contents, contending that they are evidence of a crime, though they don’t know or won’t say what the crime might be. There certainly was no “assistance” in a “suicide,” as no one died or even tried to die.

The sheriff and prosecutor argue in their Motion to Dismiss that the lawsuit must be without merit because the Supreme Court of Minnesota, in a 2014 case not involving FEN, has already declared the Minnesota law to be constitutional.

Final Exit Network contends the law violates the First Amendment-protected right to freedom of speech because Exit Guides can be prosecuted under Minnesota’s unique law solely for providing education, emotional support, and instruction on self-deliverance.

FEN’s argument is that a state law may criminalize only physical acts of “assisting in suicide” and may not prohibit speech. Minnesota is the only state known to have ever convicted people of “assisting in a suicide” solely for what was spoken.

The Anoka County defendants’ Motion to Dismiss the FEN lawsuit basically says the Supreme Court of Minnesota’s decision must be honored. FEN’s

***They don’t know or won’t say
what the crime might be.***

lawsuit says the federal district court is not bound by a ruling of the Minnesota Supreme Court interpreting the U.S. Constitution.

FEN and four Exit Guides battled a 17-count Dakota County, MN indictment in multiple courts, including the Supreme Court of the United States, from 2012 until 2019.

In the end, FEN and the Exit Guides prevailed on nearly every count of the indictment, but failed in their efforts to have the statute declared unconstitutional.

A FEN lawsuit in federal court to have the statute declared unconstitutional ended in 2019 with a dismissal for technical reasons. In that case, the federal court held that it lacked jurisdiction to consider a case that had already been litigated to a conclusion in the Minnesota courts, and FEN’s federal lawsuit was a disguised effort to relitigate the same case.

FEN’s new lawsuit argues the circumstances are different this time, and the technical jurisdictional issue of 2019 will be surmounted now that Anoka County, MN, is threatening to prosecute FEN, Ballou, and Bradley.

This time, Anoka County initiated the pending legal issue, not FEN, and the case is totally new – it has nothing to do with the 2012-19 case facts, people, or circumstances.



THE BACK PAGE

A COMPENDIUM OF RIGHT-TO-DIE WORLD NEWS

Australia

• **South Australia** is one step closer to achieving Voluntary Assisted Dying (VAD) after more than 25 years of attempts to make it legal. The bill to legalize euthanasia passed the state's Lower House in June.

Amendments to the bill include granting the right of private hospitals to conscientiously object to euthanasia and instead refer patients to other institutions. These changes mean the bill needs the endorsement of the Upper House.

If approved, South Australia will become the fourth Australian state to legalize MAiD, joining the ranks of Victoria, Western Australia, and Tasmania.

"I think it's a remarkable day for South Australia that we are now catching up with the overwhelming view of 70 percent of the public," said Shadow Attorney General Kyam Maher.

• **New South Wales** is expected to debate Voluntary Assisted Dying legislation in the fall if a bill being drafted this summer is introduced in September.

"People in NSW should have the same options of end-of-life care as people in other states in Australia. I don't think it's appropriate to deny them those," said MP Alex Greenwich, who intends to sponsor the bill.

After decades of public demand and relentless advocacy by organizations such as Dying With Dignity, NSW is one of the few states left to legislate for it, and public support – including from those who identify as Christian – is strong.

New Mexico

The state's Medical Aid in Dying (MAiD) law took effect on June 17, and with it, a new nonprofit group has been created to give information to families with ailing loved ones, and raise awareness of the new law among hospitals, doctors and hospice care providers.

Barak Wolff, board chair for End of Life Options New Mexico, said the law was carefully tailored to provide safeguards, including an opt-out provision for physicians with moral objections.

Fewer than 0.5 percent of total deaths in other states with similar laws in place – including Oregon and Washington – stem from patients using MAiD.

With the recent addition of New Mexico and Spain, individuals who live in a jurisdiction where they have a right to MAiD now number 413 million worldwide.

France

A dying French pop star made a plea in June for her country to allow Medical Aid in Dying.

Françoise Hardy, the songwriter who found fame in the 60s yé-yé movement, told the magazine *Femme Actuelle* that she was in favor of assisted suicide. Earlier she had said, "France is inhumane" for not legalizing the procedure.

Hardy, 77, told the magazine that doctors found a tumor in her ear in 2018, following her diagnosis with lymphatic cancer in the mid-2000s. Years of radiation and immunotherapy have caused her immense pain, she said, making it difficult to swallow.

"My physical suffering has already been so terrible that I am afraid that death will force me to go through even more physical suffering," Hardy said.

In the new interview, she added: "It is not for the doctors to accede to each (MAiD) request, but to shorten the unnecessary suffering of an incurable disease from the moment it becomes unbearable."

Scotland

Scottish Parliament is considering legislation on Medical Aid in Dying for the first time since 2015. The planned Assisted Dying Scotland Bill would legalize MAiD as a choice for terminally ill, mentally competent adult patients.

In response, a coalition of nearly 175 Scottish medical professionals from a variety of specialties has voiced "great concern" over the proposed legislation.

High-profile individuals have joined the campaign launched by Our Duty of Care (ODOC) after the new bill was lodged in June.

"The shift from preserving life to taking life is enormous and should not be minimized," they contend.

Recent polling shows that 86 percent of Scots would like Parliament to examine the issue of MAiD. Furthermore, 75 percent want it done within two years.

Assisted dying is prohibited by statute in England, Wales, and Northern Ireland. While there is no specific crime of assisting a suicide in Scotland, those who help a person to die could be prosecuted for homicide.

Consultation on the proposed bill is planned to take place this fall.



Judy is a FEN treasure, not only past treasurer

By Jay Niver, FEN Editor

A mainstay resigned in May from the FEN Board of Directors, but Judy Snyderman didn't leave or retire to a rocking chair.

The long-time FEN treasurer moved to the advisory board where she will continue to provide the same sage fiscal advice that she did for more than 11 years as FEN's de facto chief financial officer.

The person who signs checks is popular in most organizations, but Judy earned universal respect and admiration for more-important reasons. This polite, soft-spoken woman of few words has served as an Exit Guide since before FEN existed.

Judy began with the Hemlock Society in the early '80s, then to Compassion & Choices where she was a "Caring Friend" before C&C eliminated that program. She's been with Final Exit Network from Day One, now 17 years.

She called exit work "very rewarding – people are so grateful."

Board member Janis Landis knows Judy well and recalls when this demure woman with an MBA rose up to inspire fellow board members.

It was 2009 when police raided Snyderman's Baltimore home to seize FEN records. Charges had been filed in Georgia following a FEN-related exit, and Peach State authorities put the whole organization in its cross-hairs.

"Despite the invasion of her home and attempt to intimidate her, Judy stood firm and continued her work as an Exit Guide," Landis said last month.



Judy Snyderman

Some years later, when over-zealous prosecutors continued to harass FEN, Landis said it led to "a moment of doubt by the board: 'Should we continue?'"

"Judy's passionate plea that we not abandon our clients won the day. I was FEN president at the time, and I remain grateful and inspired by Judy's courage and commitment."

Snyderman has her own end-of-life plan: "If or when my quality of life isn't what I want it to be, then I'll exit," she said. She thinks her family will support her decision, but added, "Well, they don't really have a say in it."

Judy grew up in Baltimore but spent 33 years in Cincinnati after a company move. In 2014 she moved to Madison, WI, to be close to her daughter. She'll donate her body to the University of Wisconsin, and is now a Packers fan (dismayed with the Aaron Rodgers stand-off).

She's an even bigger fan of Cincinnati's baseball Reds – but not of the lowly football Bengals.