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# Help for the helper

## New surrogate consultant adds clout to FEN members' Advance Directives

*By Janis Landis, FEN Board Member*

In our last FEN magazine, we invited readers to share any bad experiences loved ones faced at life's end when their wishes were not followed – even with a clear Advance Directive (AD) in hand.

Readers responded (page 2), and it was never more clear that surrogates – those family or friends charged with safeguarding patients' desired care and treatment – need determined, expert support.

FEN is committed to providing that assistance to help ensure ADs are enforced.

We have implemented the first step in this initiative by hiring Surrogate Consultant Althea Halchuck. She brings exceptional skills and experience to this vital position.

Here is how Althea can help you and how you can reach her.

If you are having trouble getting an Advance Directive honored, for yourself or as a surrogate for another individual, help is just a phone call away. Althea will review the issue thoroughly with you and go over the directive.



***'Providers should never second guess or bully a surrogate trying to honor an advance directive.'***

*– Althea Halchuck*

She will lay out your options, such as speaking to the physician in charge, armed with specific information on the patient's legal rights. Or, she may help you assert your legal authority as surrogate when other family members disagree. She also can ensure that adequate pain relief is being provided, if that is what's needed.

Finally, if all these efforts do not resolve

**SURROGATE** *continued on page 2*

# What you told us re: EOL care

Following are excerpts from some readers' comments about the end-of-life treatment their loved ones received.

## Constant pain; inadequate relief

A for-profit hospice became involved when my mother was resident in an assisted-care facility. She was in constant pain, wheelchair bound, losing vision, and wanted to end her life. Hospice did not provide adequate pain relief, and she lingered for many months.

Marilyn R.

## An angelic nurse

I was a surrogate, after years of being a personal rep and other titles. At the end, it was very difficult. Thank goodness for an R.N. who saved my mother more pain, and kept me from "giving in" to the doctors. She whispered, "Don't do it."

## SURROGATE *continued from page 1*

the issue, Althea will contact our FEN attorney to determine what legal avenues are available.

Two things are especially important to remember:

1) Our consultant will not suggest what medical treatment should or should not be given. The Advance Directive is the determinant. If the patient or the surrogate wants all possible medical interventions, that is what we will work toward. If, on the other hand, the AD calls for only palliative care, we will pursue that.

2) Be assured that all these consultations, including any legal action taken by our attorney, will be done at no cost to you. We will not bill you, the patient, or the health insurance company.

You can reach Althea in two ways:

Email [fensurrogate@gmail.com](mailto:fensurrogate@gmail.com)

Phone 800-491-6713

If you don't have this info handy, you'll find it on the [finalexitnetwork.org](http://finalexitnetwork.org) website under "Services."

Althea will respond to you as quickly as possible, generally within 24 hours. If you have an acute problem, please indicate that you need an immediate reply and we will try to ensure that happens.

We welcome feedback if you use this service or have suggestions on other ways we can help.



My mother was dying and the doctor wanted to do a transfusion. The R.N. told me it would only increase her agitation. I called it off and mother died peacefully 30 minutes later. We were both fortunate.

Anonymous

## Guilted into agreeing

Doctors wouldn't listen to me about what I knew my mom would want. They seemed as though they knew best and pushed needless surgery on her, which only made her lose quality of life. I reluctantly agreed to the surgery because they guilted me into it and were dismissive of what I felt she would want. They placed incredible pressure on me and pushed until I gave in ...

Anonymous

## 'Experts' overwhelm surrogates

The patient wanted only the minimum done, only that with a high likelihood of improving their life. Instead, seriously invasive, weakening, and expensive procedures were repeatedly inflicted. The surrogates were overwhelmed with the pressure of the experts and assembly-line situation.

Anonymous

## Bullying tactics

... On the advice of my mother's doctor, we wanted to deny a treatment the hospital staff wanted to give her and they engaged in very bullying behavior. I had to get our doctor on the phone so I could withstand their bullying ...

Lyn M.

## Pain drugs not available

My sister and I had met our mother on day one at a senior home. My sister had done all the communication with this place. That evening, the hospice lady showed up. Not until then was I aware that this place didn't allow all pain drugs to be used.

I was shocked and upset. Yes, I felt my mother, 94, was ready to die and sure she didn't want to suffer unnecessarily. She was suffering from Alzheimer's, and all of a sudden could no longer walk with a walker. I wanted her to be able to access all drugs that would help her with this goal.

Peg

## Let's hear from you!

FEN is gathering stories and testimonials to display on its website and share on social media, to spread awareness about Final Exit Network and the unique, vital services we provide to qualifying persons at the end of life.

If you have an experience or story you would like to contribute, please email it to [finalexitnetworkcontact@gmail.com](mailto:finalexitnetworkcontact@gmail.com) with "Member Story" in the subject line. We will be featuring a new story each month.

To read the current story, go to our website home page [finalexitnetwork.org](http://finalexitnetwork.org) and scroll down.

## Another painful story of surrogate necessity

My mother's death was tragic and painful. Her husband (my father) was named her surrogate, yet he was 88 years old and not available. (I was the one who stayed two nights with her in hospice; everyone else went home.)

Basically, I had no idea if I had any power to change things. My mother ... was in severe pain to the point of moaning for one (full) day and one night. She was in a large, inner-city hospital, but the hospice unit was full, so she went to a different unit. Those nurses didn't seem as skilled as a hospice nurse should be ...

This "extra unit in the hospital" was useless. I kept asking the nurses to give Mom more pain meds, and they would look at her chart and say, "It's not time yet." I'm a pharmacist, and I told them that, and I knew she could get more! So, they finally called the doctor, and he added other pain and anxiety meds ...

So, this was hard to see, and I complained to the hospice manager after her death the next day, but not sure how much that helped. I had no idea I could have said I was next in line as a surrogate. Could that have been possible?

The (fall FEN magazine) article about Esta and her husband made me realize that my husband and I should go over things with surrogates. I sure don't want to die in pain!

Christine F.

## Halchuck brings vast experience as advocate

Althea Halchuck, FEN's new surrogate consultant, is the founder of *Ending Well! Patient Advocacy, LLC*, and in early 2020, she became a Board Certified Patient Advocate practicing in Arizona.

Her advocacy focuses on end-of-life care and planning, aiming to help people have "a good death."

In 2012, she earned an Executive Juris Doctorate in health law from Concord Law School, a division of Purdue Global.

Halchuck's end-of-life experience is varied and extensive. For seven years, she was a long-term care ombudsman in California, has been a certified thanatologist since 2016, and was a practicing end-of-life doula and death educator before joining Final Exit Network.

For 15 years, she has been involved in hospice, first in California where she was a law school intern in a pediatric hospice, Providence TrinityKids Care. There she helped develop and launch an art therapy program to promote health and healing for children after the loss of a sibling.



Althea Halchuck

Since 2012, she has been a hospice volunteer at the bedside of dying patients.

Halchuck has training in clinical ethics and served on two bioethics committees. The majority of bioethics cases involved making healthcare recommendations for "unbefriended" people lacking capacity and a surrogate at their end of life.

From 2014-2018, she served on a Compassion and Choices steering committee trying to bring Medical Aid in Dying to Arizona.

Kalchuck has also practiced as a mediator who negotiated end-of-life disputes as a patient advocate. She has training and experience in all facets of conflict resolution and facilitation, including mediating civil cases in Los Angeles County, and consumer and family/elder cases in L.A. County and the city attorney's office.

Since 2015, she has also served on a federal mediation panel with the Department of Homeland Security.

# Whose pain is it anyway?

– *Barriers prevent effective relief* –

FROM EXECUTIVE DIRECTOR MARY EWERT



Many of us do not fear death itself – *but we do fear dying in pain*. The United Nations recognizes access to pain management as a human right. Relief from intractable pain is recognized in aid-in-dying legislation.

While pain relief seems like something all humans would wish for others, there are strong impediments to making that wish come true.

A crucial question revolves around who decides how much pain you can or should tolerate. Should that decision belong to your physician? To your hospice staff? To you?

The informative interview with Dr. Forest Tennant (back cover) highlights problems in identifying and treating pain with a focus on the patient’s – not the

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*Mum had said she was ready; we were ready. There’s medicine in the world that can make this easy. Whom was she being kept alive for?*

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healthcare provider’s – experience. In the fall FEN magazine, we were fortunate to have Barbara Mancini share her experience trying to honor her father’s wish for a peaceful death. A nurse herself, Mancini mentioned to her father’s hospice nurse that she had administered morphine at his request. What followed was a travesty of justice as Mancini was subject to a year-long criminal investigation.

A dear friend recently shared how the treatment of his 98-year-old mother’s pain varied depending upon the hospice nurse. We hear claims that hospice and palliative care can relieve most pain. But most is not all. Some patients continue to suffer while the perspective on the patient’s pain is based in the perceptions of those treating them.

There are so many stories. The three daughters of Heather Black shared their story of their mother’s death from esophageal cancer. For them, the memories of their mother’s last days are those of panic, pain, and helplessness.

“Mum had said she was ready; we were ready.

There’s medicine in the world that can make this easy. Whom was she being kept alive for?”

Dignity in Dying Scotland, where the Black family lives, estimates that 11 people a day die there in pain. There are people for whom palliative care just doesn’t work.

UK campaigners published a small but powerful book – *Last Rights: The Case for Assisted Dying* – that tells other stories of painful deaths.

- Geoffrey Whaley, who was reported to police as he prepared to travel to Switzerland to avoid the final stages of ALS.

- Fiona Strong, a cancer patient for whom terminal sedation did not work.

- The daughter of a woman whose thyroid cancer spread, eventually making it to her bladder. Doctors responded to the daughter’s request for more morphine with this: “We need to be careful, because if we give her too much morphine and she passes away, it could be looked at as the cause of death.”

Nicole Gladu, who is wheelchair-bound with a degenerative condition, is one of two Quebecers who challenged the constitutionality of the “reasonably foreseeable” death required by Canada’s federal aid-in-dying legislation. “Vulnerability is a concept used *ad nauseam* by paternalistic people in good health (for) standing in the way of MAID,” Gladu says.

The stories of pain and suffering continue. The medical and legal professions, often cowed by religious organizations, maintain the status quo.

We must continue to fight for what is our human right to a peaceful, dignified death. FEN members are in the vanguard of this movement. Our voices demand that we have a choice in how we die.

*I extend a heartfelt **thank you** to all who responded generously to FEN’s annual appeal. You are key to our movement. Your generosity helps give the gift of choice at the end of life.*



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Final Exit Network supports and collaborates 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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### VISION

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

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# One giant leap for MAiD (?)

## Options are expanding for hastening death



Thaddeus Pope is more than a pre-eminent jurist and bioethicist. He's also a devout family man, adventurer, and outdoor enthusiast.

By Thaddeus Mason Pope, Guest Contributor

Despite the pandemic, 2020 was a big year for the right to die, especially for Medical Aid in Dying (MAiD). New Zealand enacted a permissive law. Top courts in Austria and Germany ruled that individuals have a fundamental right to MAiD. And legislation advanced in other jurisdictions from Spain to Tasmania.

Today, over 350 million individuals live where they have a right to MAiD. But many still struggle to access options for hastening death. Here are three big hurdles facing Americans.

### Self-administration vs. clinician administration

The New Zealand law that takes effect this year permits MAiD that is either patient-administered or clinician-administered. Based on experience in Canada, the Netherlands, Belgium, and Luxembourg, more than 99 percent of New Zealand MAiD will be clinician administered. Almost nobody chooses to self-ingest when someone else can do it for them.

But contrast this with all 10 jurisdictions in the U.S. All require that the patient self-ingest the medication, usually orally. That is not as effective or as safe. *We have the most restrictive MAiD laws in the world.*

### More accessible MAiD

While nine U.S. states and the District of

Columbia permit MAiD, many seriously ill patients there are unable to access it. They cannot satisfy eligibility requirements or onerous safeguards.

In response, several states have been relaxing eligibility conditions and safeguards. Beginning in 2020, Oregon waived its 15-day waiting period for those who cannot survive that long. In 2021, several states are moving to permit not only physicians, but also advance-practice registered nurses to provide MAiD.

Some states are expanding the definition of “terminal illness” from six to 12 months, and beyond. In sum, there is a renewed focus on not only bare legal permissibility, but also on practical availability.

### Continuing need for VSED and FEN

Even with these new moves to expand access, MAiD remains out of reach to many interested individuals. Many cannot access it either because it is illegal in their jurisdiction, or they cannot qualify.

Therefore, it remains important to draw more attention to alternative end-of-life options. Notable among these is Voluntarily Stopping Eating and Drinking (VSED).

When supervised by palliative-care professionals, death by dehydration is peaceful and comfortable. Growing published medical research from Switzerland and the Netherlands shows that the prevalence of

MAiD continued on next page

## Where there's a there's a way



The generous gifts that members and friends bequeath to Final Exit Network upon their passing accounted for more than half of every dollar FEN spent in its most recent fiscal year.

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, just call us toll-free at 866-654-9156 or email us: [finalexitnetworkcontact@gmail.com](mailto:finalexitnetworkcontact@gmail.com)

## MAiD *continued from prior page*

VSED rivals that of MAiD.

VSED is already legal in every state. There's no need to pass a law in any legislature. But we lack guidance from government regulators or even from private medical associations. Because clinicians do not like to act in the face of uncertainty, this silence is chilling.

Therefore, I am so pleased to see Final Exit Network working not only to expand the menu of end-of-life options, but also to clarify options like VSED that are already on the menu.

Especially valuable is FEN's Supplemental Advance Directive for Dementia (SADD), which permits individuals to avoid premature hastening of death by leaving instructions to implement VSED after they lose capacity.

### Conclusion

For too long, the right to die has been framed in binary terms: *Is there a right? Yes or no?*

Increasingly, we are making sure that options such as MAiD and VSED are not only legally permissible, but also practically available.

*Thaddeus Pope is a law professor in Saint Paul, Minnesota. He writes about medical aid in dying, VSED, and other end-of-life issues.*

[www.thaddeuspope.com](http://www.thaddeuspope.com)

## The significance of obituaries

By Derek Humphry, Advisory Board Chair

I'm a daily scanner of the obituaries in the four newspapers that I read in the U.S.A. and U.K. (all now online, unfortunately). Why this obsession?

True, at 90, I'm on the cusp of life and death myself, yet the instinct to study the lives of others recently deceased goes longer and deeper than that.

After perusing the lists of the recently dear departed, I only read the obits of people who interest me: How did they achieve what they did? How long did it take them? What was their particular significance?

Particularly fascinating to me are the stories of WWII veterans who were in dangerous combat situations, through skill and luck survived, then went on to live to be 90 or even 100.

Bear in mind that early in life, it was my job to write obituaries. As a newspaper reporter from age 16, I was often sent to the homes of just-bereaved families to seek out the backgrounds.

I was never turned away. People seemed honored that their loved one deserved being in the local paper.

Later in life, I've felt obliged to compose the obits of colleagues in mutual campaigning movements, giving these articles a deeper description through familiarity.

There's some strange feeling in the words of the unknown person who opined: “You are not really dead until everybody who knew you is dead, too.”



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Walt Misiolek and Bev Thorn

By Beverly Thorn, FEN Member

For years, my husband insisted he wanted a death with dignity, and for years, he researched options. He even had an underlined copy of the *Peaceful Pill Handbook* when I became involved with him over 20 years ago.

When he started noticing mild but concerning cognitive issues in 2003, he became heavily invested in learning his options for dying on his own terms. It was 10 years before any abnormalities were detectable on an MRI or with neuropsych testing, and even thereafter, he functioned pretty well until 2016.

He was adamant about wanting to avoid being placed in nursing home care – and he certainly didn’t want to end up being kept alive through useless medical interventions and spoon feeding, the way his own

ending one’s life with nitrogen, without any expectation or need for him to ever actually do so.

Ultimately, my husband decided that he wouldn’t go off to Switzerland because he didn’t want to leave his daughters that way, and he didn’t want to use the FEN nitrogen method because it might cause legal (“assisting a suicide”) problems for me or the girls if they knew about it, so that left Voluntarily Stopping Eating and Drinking (VSED).

He talked to his physicians, who were theoretically “supportive,” and we talked to the kids, who understood, and he/we tightened up his Advance Care Directive to indicate that by the time he entered a moderate stage of dementia, he would likely institute VSED.

The booklet published by FEN on VSED was a valuable tool as I took on more of the responsibilities for

mother had been.

To gain my cooperation and support, Walt agreed he would not take his life violently. He researched if any U.S. state allows doctor-assisted dying for someone with dementia, if the person has clearly specified their wishes ahead of time.

He became a member of Dignitas in Switzerland, exploring options for qualifying for an assisted death prior to severe dementia. We joined Final Exit Network (FEN) and even applied for and received assistance from Exit Guides.

I was astounded that two caring strangers would come to us and give us detailed information about non-violently

*Toward the very end, he would sit with a small plate of prepared, cut-up finger food, and perhaps get a bite or two while also trying to chew the napkin, placemat, or cup.*

# A FEN-informed death

facilitating his relatively peaceful death.

He ultimately did not act before losing the necessary cognitive skills to stop eating and drinking – I think that he just didn’t want to leave any shred of quality time on the table! But our Advance Directive left very specific prohibitions regarding eating and drinking after the onset of moderate dementia.

Well into moderately severe dementia last fall, as long as Walt showed interest in food and drink, we focused on pleasure eating only – forget about adequate nutrition and none of those blasted protein shakes!

We were to wait on his cue for interest in food. (Later in the process, he would poke around in the pantry or fridge, and we would then offer, but not until then.) We were not to spoon feed him.

During the last year, he lost the ability to identify and use utensils properly, and in the last couple of months, he sometimes forgot the mechanics of food-to-mouth, chewing, swallowing (although he never choked). Toward the very end, he would sit with a small plate of prepared, cut-up finger food and perhaps get a bite or two, while also trying to chew the napkin, placemat, or cup.

I dreaded the admonition that he not be spoon fed if he indicated a desire for food, but could not feed himself. To my relief, his interest in food and drink seemed to naturally wane, but with it came serious confusion, hallucinations, and agitation.

Had it not been for a close, long-term relationship with his primary care physician – who spotted the need for hospice ahead of time, and who directed all medical decisions based on the specifics in his living will – he would have spent his last days strapped to a gurney in the emergency department and transferred to a nursing home bed somewhere, alone and raving.

Instead, we were able to keep him at home, with a physician who was comfortable and willing to follow his directive to “keep me comfortable even if doing so hastens my death.”

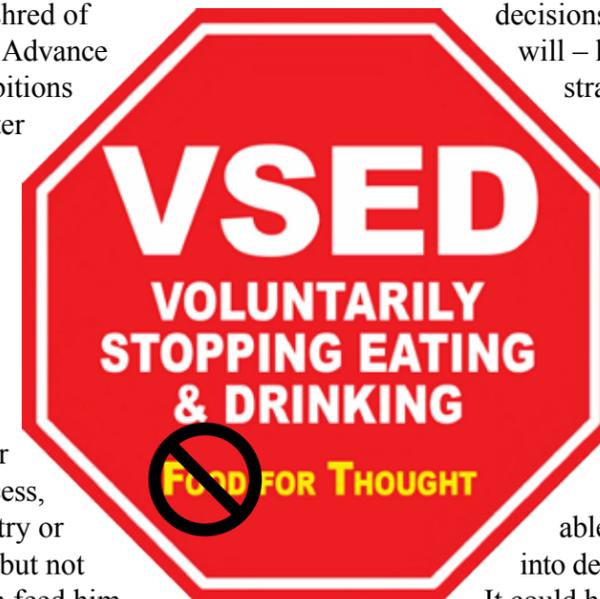
He did not overdose, but he was able to let go of his fight and relaxed into death a few days after being sedated. It could have been so different, so much more

horrible.

As his wife, I was one of the lucky (and informed) ones. I marvel at how easily he could have been sucked onto the medical treadmill of useless and painful interventions, at how he could have died alone in agony.

But a thousand unseen angels were at work along this way, one of them being Final Exit Network.

FEN does so much more than offer information about how to quickly terminate one’s life. They offer knowledge, empowerment, support, and follow-up. For these and so many other things, I am grateful.



DEATH DOULAS

**A caring doula, a loving sister, plus VSED option let ‘Wendy’ depart**

By Jim Moschella, FEN Exit Guide

‘Hi, Jim, it’s Wendy. You’ve got to help me die!’ Her voice on the phone was determined.

Wendy had been diagnosed with an incurable, degenerative disease several years back, and her health had slowly and steadily declined. Wendy had moved to Texas to be close to her sister, Patty, and had been placed in an assisted-living facility, but it was not giving her the care she needed now that she was wheelchair-bound and could barely feed herself.

As such, she could not have qualified for FEN Exit Guide Services, and I explained to her that the only real option was Voluntarily Stopping Eating and Drinking (VSED). Wendy said Patty would never agree to VSED – and that she controlled all of Wendy’s finances.

FEN’s *Guide to Preparing for VSED* listed death doulas (now termed “end of life” doulas) as a helpful resource, noting that the International End of Life Doula Association (INELDA) and the National End-of-Life Doula Alliance (NEDA) had online directories of members. I contacted Melissa Wood from the NEDA directory; she spoke with Wendy and quickly established a very supportive rapport.

Melissa provided the name of an attorney so that we could arrange for me to obtain medical and financial powers of attorney to obtain the care Wendy needed. Fortunately, after Patty called me – and I explained Wendy’s wishes and the VSED



process – Patty had a change of heart and began fully supporting Wendy’s end-of-life plans.

Melissa found a hospice service that was agreeable with VSED and arranged for hospice to interview Wendy at the assisted-living facility.

Wendy had severe problems with her short-term memory, and Melissa worked with Wendy to write down her health concerns to make sure she didn’t forget anything during the interview. Wendy qualified for hospice care and began

***Wendy’s health continued to decline and her body began to shut down on its own without actually beginning VSED.***

receiving more appropriate drugs to treat her pain.

Melissa had also investigated several smaller, private care homes that would provide the attention Wendy needed, and she met Wendy and Patty to tour the private facilities. She even went back for a second visit to make sure Wendy was satisfied.

Melissa was in constant contact with both Wendy and Patty to reassure them and answer any questions every step of the way. She prepared a document clearly describing the VSED process, and listing all the supplies Wendy would need to assist with VSED.

Melissa also helped create a video recording of Wendy explaining why she wanted to pursue VSED, and that she should not be given food or water after she began the process.

Wendy’s health continued  
DOULA continued on next page

*FEN asks: What might hasten death?*

**Survey reveals life-ending motives**

By Robert R. Blake

FEN’s recent survey of factors that might lead our members to consider hastening their death provided some interesting information and raised issues for further research and reflection.

Not surprisingly, 97% of 341 participating respondents were over the age of 60, with the vast majority being between 70 and 90. About 6% were over 90, and one person was (delightfully) over 100.

Reflecting the spiritual orientation of other people seeking support for a hastened death in previous state surveys, 68% of members who chose to identify themselves spiritually listed “none” or non-traditional categories such as “humanist, agnostic, spiritual, or atheist.” But nearly a third left this question blank, suggesting that there may be a great deal more members who are very thoughtful moral thinkers, who do not have a traditional religious orientation, and are accustomed to skipping this kind of question.

**DOULA** *continued from prior page*

to decline and her body began to shut down on its own without actually beginning VSED. A sign was placed on her door advising not to feed her, but Melissa still had to convince the visiting hospice service and private care home to stop giving her food and liquids.

Wendy slipped into unconsciousness, and Melissa stayed and performed Reiki on her one night while Patty went home to get some rest.

Wendy passed away peacefully, shortly before Melissa got there to spend another night with her. Melissa then went and stayed with Patty until the funeral home arrived to take Wendy’s body.

Melissa’s services to Wendy, Patty, and me were invaluable. Without her assistance, Wendy would have suffered a much slower, painful, and emotionally distressing death.

[Melissa’s website](#) provides much helpful information about end-of-life doulas and how to achieve a peaceful deliverance. These doulas are an excellent “boots on the ground” resource for anyone in chronic pain and/or wishing to pursue VSED.

*Editor’s note: Wendy and Patty’s names are fictitious to protect their anonymity.*

Traditional spiritual identifications were not as frequent: Protestant, 8%; Eastern religions, 5%; Jewish, 5%; Catholic, 2%; and Quaker, 1%. No respondent identified as Muslim.

Also not surprising is that almost every reason listed for possibly wanting to hasten one’s death was ranked as either moderate or high importance to members. The most important factor was “loss of independence or an intolerable quality of life.” The least important factor was “significant loss of hearing or vision.”

Physical discomforts such as fatigue, incontinence, nausea, trouble breathing, and uncontrolled pain were identified as highly important factors in expecting to want to hasten one’s death. But psychological and social factors were equally important, such as “inability to create meaning,” “feeling like a burden to others,” or “having to move to a nursing home.”

As we begin to analyze the results of these questionnaires from people who have already applied for Guide service, it will be interesting to see if this broad range of physical and psycho-social factors are actually in play for those who are actively ready to hasten their death.

Maybe when we are truly ready to die, factors leading to that decision may be more nuanced or limited.

| Factors of High Importance to FEN Members In Deciding to Hasten Their Death |        |
|---|--------|
| Loss of independence, intolerable quality of life                           | 89.10% |
| Uncontrolled pain   | 76.57% |
| Fatigue, incontinence, nausea, trouble breathing                            | 76.02% |
| Inability to create meaning   | 74.11% |
| No further effective treatments   | 71.39% |
| Feeling like a burden to others   | 67.03% |
| Needing to move to a nursing home   | 66.76% |
| Confusion   | 66.21% |
| Forgetting  | 63.22% |
| Six to twelve-month prognosis   | 58.58% |
| Running out of money  | 51.23% |
| No remaining close friends, family, or pets                                 | 44.69% |
| Inability to prepare food, climb stairs, walk                               | 41.69% |
| Significant loss of hearing or vision                                       | 27.25% |

## Good Endings Film Club



### Blackbird

Reviewed by Jim Van Buskirk

“Once we set a date, I stopped worrying about dying, and I could focus more on living.”

So says Lily, the matriarch around whom *Blackbird* revolves. Having decided to end her decline due to a degenerative disease on her own terms, Lily (Susan Sarandon) and her physician husband (Sam Neill) have summoned their loved ones to their isolated beach house for one final gathering. Unresolved issues between their daughters (Kate Winslet and Mia Wasikowska) complicate the fraught situation.

This emotionally satisfying film is propelled by its well-realized characters, including Lily’s BFF, subtly rendered by Lindsay Duncan.

*Blackbird* is based on the award-winning 2014 movie *Stille Herjete* (Silent Heart) directed by acclaimed Danish director Bille August, and written by Christian Torpe. Producer Sherryl Clark happened to be chatting with Torpe at a dinner party when he mentioned that he’d adapted his script for a U.S. production.

Clark politely said she’d take a look at it. “But he sent it to me, and I was so moved by this story of a family struggling with their mother’s decision to take her own life after being diagnosed with ALS.”

Though Lily’s disease is not specifically identified, prominently acknowledged in the credits is the Amyotrophic Lateral Sclerosis Association of America.

Sarandon is as beautiful as ever, her pitch-perfect performance anchoring the film. She reportedly conducted research for her role by meeting a “beautiful and courageous woman who is going to Dignitas,” referring to the Swiss non-profit clinic which provides assisted/accompanied suicide to qualifying members.

While it is specifically mentioned that supporting

Lily’s self-deliverance is illegal in the unnamed state, the film avoids becoming embroiled in political and legal controversies. “Everybody has the right to make a decision without your family members being charged with homicide,” Sarandon told the Toronto Film Festival.

This is not Sarandon’s first foray in the right-to-die movement: She played Janet Good, founder of a Hemlock Society chapter, with Al Pacino as Jack Kervorkian, in Barry Levinson’s 2010 HBO film *You*

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***Both films are remarkably respectful of the important subject matter, and are highly recommended to initiate conversations about the possibility of a hastened death.***

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*Don’t Know Jack.*

Kate Winslet was instrumental in finding the location for this film, a home near her own in West Sussex, which convincingly doubles for the Hamptons. The tasteful house is an integral character in the story, as it is in the Danish version, encouraging the eight characters to interact as if in a play, and it is not surprising to learn *Blackbird* was filmed almost chronologically.

Unexpectedly, the American version directed by Roger Michell, which is similar to the Danish version

almost scene for scene, is even more understatedly powerful. Differences include the non-binary gender of Wasikowska’s character’s partner and an important element of the ending.

The Danish version felt a bit heavy-handed with clocks in every scene and a somber classical soundtrack, though there’s plenty of Bach here, too. Both share realistic performances, high production values, and graceful humor.

Both films are remarkably respectful of the important subject matter, and are highly recommended to initiate conversations about the possibility of a hastened death.

I concur with Michell’s comments: “What might initially look like a routine ‘disease-of-the-week movie’ is, in fact, a much funnier, odder, richer, and more nuanced portrait of a family.”



## New book provides unbiased look at state of RTD movement

By Jay Niver, FEN Editor

Veteran journalist Katie Engelhart was working in London when she was assigned to report on the debate over physician-assisted death because the British Parliament was to vote on such a measure.

It was 2015, and lawmakers nixed it. But the topic piqued Engelhart’s interest. It triggered an almost five-year quest to learn how we die around the world – with or without the help of laws, doctors, or potent drugs.

The result is her first book, *The Inevitable: Dispatches on the Right to Die*, which will be published March 2 by St. Martin’s Press (US/Canada) and Atlantic Books (UK/Europe).

The author was surprised to discover how alone and lonely dying people felt – despite the fact that death is universal.

“Everyone I met was wrestling with big questions,” Engelhart said. “They were coming up with remarkable answers, but often doing it completely alone ... All the time I would have people take me aside and tell me



Katie Engelhart

and their doctors. She found, she said, “this enormous gap in what they were sharing and understanding about one another.”

She’s hoping that physicians will read *The Inevitable*, and others who do may feel “a little bit less alone” in their end-of-life challenges.

Though Engelhart is “firmly in the camp of patient rights and patient choice,” she said she “approached the book as a journalist and a writer, not as an advocate.”

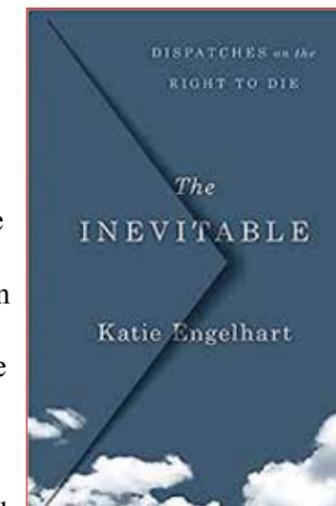
[The book can be ordered here](#), and a sample excerpt involving FEN can be read in this [California Sunday Magazine article](#), “[Her Time](#).”

Reviewed by Michael James

Finally, an engaging, incisive book about the right-to-die movement. The book focuses on six people grappling with the issues surrounding the movement – two physician leaders and four adults struggling with unbearable suffering and societal pressures.

The author’s deep dive into the emotions and rationale of each of her subjects presents a compelling look at all sides of the debate surrounding the right to live and die with dignity.

Ms. Engelhart’s in-depth interviews in North America, Australia, and Europe offer a 360-degree perspective that may challenge the reader’s perceptions about euthanasia, suicide, and what it means to live a “complete life.”



Since joining Hemlock in the ’80s, I’m familiar with much of the literature on the quest for a “good death.” *The Inevitable*, by focusing on the personal motivations of those profiled, makes for a great read – for those new to the issues or those steeped in the history of the movement.

The chapter on Modern Medicine focuses on Dr. Lonny Shavelson’s California assisted-death clinic and his clients, presenting an empathetic look at the emotional and social issues confronting those who want to control their death.

FEN’s client-centered practices are accurately portrayed in the chapter on Memory. The struggles of Debra, the FEN client dealing with rapid onset dementia and diminishing resources, and the FEN team who educate her and support her determination to control her end of days is a gripping read.

The history of the right-to-die movement – its leaders, detractors and the “euthanasia underground” – is well covered.

*The Inevitable* is a compelling read about real people facing life’s ultimate challenge – how to face the inevitable.

# IT TAKES ALL KINDS

## How a 'kick-ass' woman cheerfully took charge amidst COVID, inspiring her FEN exit team duo

By a FEN Coordinator and FEN Exit Guide

“Molly” first contacted Final Exit Network last January. She would be 90 when she exited months later, still as cheerful and independent as she had been all her life.

Molly suffered from a constellation of medical problems, which she summed up by telling me (her Coordinator): “Nothing works. I’m exhausted trying to take care of this house. Everything hurts except sitting in a chair, and even that hurts after 20 minutes. It stings to eat even simple food; I’m having increasing difficulty thinking of the right words, and I just dread losing the ability to care for myself even in minimal ways.”

In spite of this description, she always sounded upbeat. She had been a college professor, the widow of two men, one of whom she nursed through dementia, and a mother, proud of her adult children.

I loved talking to her because she could laugh at most difficulties, completely devoid of self-pity. It might sound disrespectful, but I thought of her as a “kick-ass woman.” *Little did I know how well she deserved that unspoken compliment!*

Molly didn’t have many medical records, because every time she saw her primary care provider in the last few years, she was advised to take only Tylenol for her severe pain. So, she went to the doctor less and less.

She went back for one final visit at my urging, just so we would have a recent medical record to add to her paperwork.

When I told her she had been approved by FEN’s Medical Evaluation Committee, she was delighted. But I was worried because by this time, our country was in a COVID-19 lockdown – I wasn’t sure our Guides could even get to her.

She took the news with her usual aplomb. I’ll turn

this over to her Exit Guide, who will finish Molly’s story.

Molly was a hard-headed, big-hearted matriarch who bent over backwards for her clan but wouldn’t budge when she knew where she stood. And she knew where she stood on this.

Her no-longer kids, with kids of their own, were not thrilled with her plan. They sort of understood – they had seen drawn-out debilitation and hard death – but Molly had been a force of nature. Her daughter had complained that if she didn’t insist on doing everything herself, she might not hurt so much.

Which is not to suggest that they would oppose her decision; that would have been futile.

Molly called me shortly after I mailed her a list of items to purchase. I presumed she had a few questions. I was

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***Molly was a hard-headed, big-hearted matriarch who bent over backwards for her clan but wouldn’t budge when she knew where she stood. And she knew where she stood on this.***

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wrong.

“I’ve got everything and, looking through the book you suggested, it seems pretty straightforward. I can take it from here.”

*WHAT?* I was being summarily dismissed! I reviewed the list with her, and I asked her about what she had read. I insisted she talk through the steps with me. I all but begged her to let me come.

Nope. Her kids were not going to move a mountain, and neither was I. Humbling though it was, the best I could do for Molly was get the hell out of her way.

She had planned to exit Wednesday, but she called, cheerfully, of course, to let me know that one of her grandsons wanted her to meet his girlfriend. For that, Molly would delay her plan for two days – so Friday it was.

*Editor’s note: Identifying information has been changed.*



### Austria

The Constitutional Court of Austria has ruled that the country’s ban on assisted dying is unconstitutional.

In a December decision reminiscent of the Canadian Supreme Court 2015 ruling that led to Canada’s assisted-dying law, the Austrian court found that the ban on assisted death is “a violation of an individual’s right to self-determination” since it laid down a blanket ban on assisting a person in dying without providing for any exceptions.

The decision came after various affected stakeholders, including two terminally ill individuals, requested removal of the provision.

### Spain

Euthanasia and assisted suicide will be legal in Spain once the country’s Senate ratifies a historical bill passed in December by the Congress of Deputies, the nation’s lower house of parliament, by a solid 198-138 majority.

After decades of social debate and four previous failed attempts, the bill was passed with cross party support from leftist and conservative parliamentarians.

Following its predicted ratification this spring, Spain would become the sixth country worldwide to acknowledge the right to an assisted death, after the Netherlands, Belgium, Luxembourg, Canada, Switzerland, and New Zealand.

The bill is similar to the Canadian law in force since 2016 and the law just passed in New Zealand, in that it allows for either doctor administration or self-administration. Evidence from Canada is instructive: A vast majority of people who hasten their death prefer doctor administration.

### Washington

Even where Medical Aid in Dying (MAiD) is legal, it is getting more difficult to find healthcare providers who are able to help qualifying patients.

Health systems CHI Franciscan and Seattle-based Virginia Mason have merged into Virginia Mason Franciscan Health.

Tacoma-based CHI is a Catholic entity. One in six U.S. hospital beds is now in Catholic facilities, but the figure is 41 percent in Washington.

The merged companies will operate 11 hospitals

and nearly 300 care sites, including primary and specialty care clinics and same-day surgery centers.

Virginia Mason said it will remain a non-Catholic organization but said it would not provide “direct elective pregnancy terminations (or participate) in physician-assisted death.”

The merger had been opposed by more than a dozen organizations that warned that the merger could jeopardize access to needed services including abortion, contraceptives, end-of-life care, and LGBTQ services.

### Massachusetts

More than two dozen active or retired RNs have come out publicly to support the End of Life Options Act that will go before Massachusetts lawmakers this spring.

“As both active and retired registered nurses, we are among the 70 percent of Massachusetts citizens ... who support legalizing the option of medical aid in dying for people who are terminally ill and mentally capable of making their own end-of-life healthcare decisions,” the group wrote to the *Milford Daily News*.

“We’ve cared for terminally ill patients for a cumulative total of nearly 200 years, and seen too many leave this world in severe pain and often prolonged, unrelieved suffering.”

The bill is sponsored by 20 state senators and 47 representatives.

### Canada

Delta Hospice Society (DHS) in Ladner, British Columbia, is facing layoffs and potential closing because it refuses to allow physician-assisted dying for its clients.

The DHS board released a statement saying, “We have been left no other choice due to the Fraser Health Authority canceling our service agreement and 35-year lease. Fraser Health is about to evict us and expropriate approximately \$15 million of our assets simply because we decline to euthanize our patients.”

DHS said they “accept that ... MAiD is an elective, legal service across Canada. Nothing in Canadian law, however, requires medically assisted death to be made available everywhere, at all times, to everyone.”

The funding agreement between DHS and Fraser Health is set to expire on Feb. 25.

# The painful truth about alleviating pain

*By Jay Niver, FEN Editor*

Dr. Forest Tennant knows something about pain. He is revered by his patients and much of the medical community for his expertise in treating it.

Unfortunately, the U.S. Drug Enforcement Agency does not share their admiration.

The DEA effectively shut him down almost three years ago after raiding his home and clinic near Los Angeles.

Dr. Tennant's high-dose opioid prescriptions caught their attention, plus the fact that patients traveled far and wide so he could treat them.

One high-profile doctor referred him patients from Michigan.

"I had referrals many years ago from Dr. (Jack) Kevorkian," Tennant recalled. "He called me and said, 'I'd like to refer some people to you. You know, I only want to help people who are at the end and want to end their life. But I have some people who, if they could just get their pain treated, might like to stay alive.'"

The DEA never brought charges against Tennant or his clinic, but lawyers and other doctors advised him to retire to his home in Wichita.

Though he is no longer seeing patients, he is not parked in a rocking chair. He and his wife, Miriam, operate the [Tennant Foundation](#), which has two major research and education projects focused on Intractable Pain Syndrome (IPS) and Adhesive Arachnoiditis.

Despite renowned success in

battling pain, Dr. Tennant knows there are limits.

"We do have a group of people whose pain we cannot relieve," he said. "Many of them have had strokes, and a lot of them have what we call Intractable Pain Syndrome; part of the nervous system is destroyed."

Despite every possible medical intervention, "the pain cannot be relieved," Tennant said. "Those people make the choice: If they can't get pain relief, they don't want to be here."

From his experience, Dr. Tennant said there are two other groups of people who may choose to end their lives.

One is patients with intractable pain "who just get tired of the fight. They spend every hour of their day trying to find comfort ... They've lost their friends, become isolated, reclusive, bed-bound; they are just tired and wish to end their lives."

The second group, he said, is "people who come to me and say, 'I've done everything in life that I wish to do ... I'd prefer not to be here.' But that's not a doctor's decision. It's their personal decision."

If circumstances warrant a planned exit, Tennant said we should "support their view and their right."

What's more, it should be regulated: "Still, today, this issue is taken care of within families in a clandestine manner. And anytime you force something underground, it's not as good if it were in the open."



Forest Tennant, MD