

IN THIS ISSUE

- New initiative will help surrogates Page 2
- Cruel death may have positive outcomes 4
- A twin sister's touching tribute 7
- POINT-COUNTERPOINT: Is a 'completed life' enough? 8-9
- DwD's Peg Sandeen reflects on the movement 10
- FEN coordinators do so much more 13

RELIEF FROM HOSPICE

Choosing a surrogate can ensure that your end-of-life wishes are heard – *maybe honored*

By Jay Niver, FEN Editor

When doctors found inoperable Stage 4 cancer in Bob Bruno, he was sent that same day to the only hospice in Sarasota, Fla. His wife, Esta Asteroff, suspected there could be trouble: Her aunt had a horribly painful time there in 2008.

“She was screaming so badly some days with horrific hallucinations,” she recalls. “I kept begging them to give her more morphine ... It was heart-rending to watch.”

Now, 12 years later this past June, would it be any different for her husband?

“He was in such distress and agitation and pain and discomfort, and every day was a fight with the doctor for additional medication,” Esta says.

It got worse on Day 5. “From 11 p.m. until 1:30 a.m., he was in such dire straits, and the nurse gave him everything she could, then



Bob Bruno and his wife, Esta, posed on a cruise a year before he was diagnosed with Stage 4 cancer and went immediately to hospice, where he was denied sufficient pain relief until she asserted her rights as his legal surrogate.

looked at me and said, ‘He’s transitioning,’ which is a very strange euphemism for dying ... He was in agony and calling out and thrashing around, and I said, ‘Can’t you help him?’

“She claimed not. Later, I found out that was simply not true. She could have called the on-call physician to get additional medication for Bob. She chose not to do so and lied to me.”

What happened next, says Esta, was unconscionable: “The nurse said, ‘Maybe you’d like to move your husband to another facility?’ I said, ‘I would *love* to move my husband, but there’s none other in Sarasota.’”

Bob was not *transitioning*. His ordeal would last another five days, and things finally

HOSPICE *continued on page 2*

improved after an indirect FEN intervention.

Help from some friends

Esta had a college friend she'd known for decades, a woman who had since worked years with FEN (Esta herself was a long-time FEN member). Esta reached out to her friend, who put her in touch with FEN attorney Robert Rivas.

Rivas does much for Final Exit Network – but nothing is more vital than fighting for the rights of dying people and their appointed surrogates.

Sometimes called a *proxy* or *agent*, a surrogate is someone assigned through an Advance Directive to make decisions for a dying person who is no longer competent to do so.

The irony of Esta's case is that *she was the surrogate* for both Bob and her aunt – and it made no difference to the hospice.

"We had all the paperwork done in 2018," Esta explains. "We did wills, Advance Directives, health-care proxy; everything was in order.

"Rob told me I had the right to demand that Bob get all the pain medication he was legally entitled to, which was far more than they were giving him. If it was, like, from 1 to 100, we were still at 7 ... I had a right to insist on that, and they had an obligation to do it. They simply did not want to provide morphine to him."

On Day 6, armed with legal encouragement, she confronted the doctor and "it seemed to escalate them," Esta recalls. "I think they got a little scared. They knew that *I knew* I had rights."

Bob's meds were increased "to where he was at least peaceful."

Hospice reputation tanks

Esta's opinion of the Sarasota hospice sank even further when she learned that it had stopped another hospice from setting up there in 2018. She says "the number of beds" should not determine need if care is substandard and there is "no choice for the public."

She believes that a profit motive can interfere with altruistic ones, and data seem to support that.

In the 1980s and '90s, nonprofits provided virtually all U.S. hospice care. By 2016, more than two-thirds were for-profit, and only 20 percent were

nonprofit. Since then, every new hospice has been profit-oriented.

The money is good. The profit margin of for-profit hospices is more than four times higher than for nonprofits struggling to stay afloat.

"Hospices make more money from patients who live a long time than those who die quickly," *The Huffington Post* reported. "That incentivizes (them) to cherry-pick the healthiest patients to boost gains."

The *Post* added: "In dozens of lawsuits, federal

prosecutors have accused hospice companies – including almost all of the largest players – of billing fraud, alleging they enrolled patients who didn't

qualify and signed them up for extra-expensive levels of care."

In 2017, for-profits discharged more than 1 in 5 of their patients alive. More than 460 companies discharged *over half* their "customers" before they died.

For her husband Bob, Esta believes there was also a cultural stance aligned against them in Sarasota.

"I think they have a philosophy where all life, no matter how bad, is to be lived as long as you can possibly live it," she says.

Surrogate help coming soon to FEN members

By Janis Landis, FEN Board Member

"Hey, here's a copy of this form designating you as my healthcare surrogate," your sister or spouse or best friend (maybe all three) says to you.

It might also be a Power of Attorney calling you an "agent" or "proxy."

You nod and dismiss it. The people who designated you are healthy, live not too far away, and are very competent individuals. Your responsibility is light on your mind.

But flash forward some years. Maybe your spouse is showing early signs of dementia; maybe your sister has moved to another state; and your friend wants to push for admission to experimental and painful chemo treatment instead of palliative care only. And you've just started a new job with intense work demands.

All this underscores that agreeing to be a health-

SURROGATE *continued on next page*

SURROGATE *continued from prior page*

care surrogate is a very serious responsibility – possibly a burdensome one. Maybe even one where your belief in a peaceful death conflicts with your friend’s choice.

An Advance Directive is only as strong as the surrogate who enforces it.

You may need to make life-or-death decisions under extreme time pressure and emotional stress. And you may not have any clear idea of what that decision will accomplish.

- Maybe a ventilator gives the patient time for their body to get stronger and breathe on its own again.
- Maybe that recovery won’t happen, and someday you’ll be going to court to have life support turned off.
- Maybe you know the right decision: You want to support your spouse’s directive for palliative care only, but you’re being pressured by medical staff to authorize an operation.
- Maybe your sister is in palliative care, but not getting adequate pain relief.

Increasingly, as we live longer and more medically complicated lives, as families scatter and friends die, we find it difficult to choose a competent and willing surrogate – and it is even harder to be one.

FEN knows of the growing number of members who are having difficulty designating a surrogate, and/or fulfilling their role as one themselves.

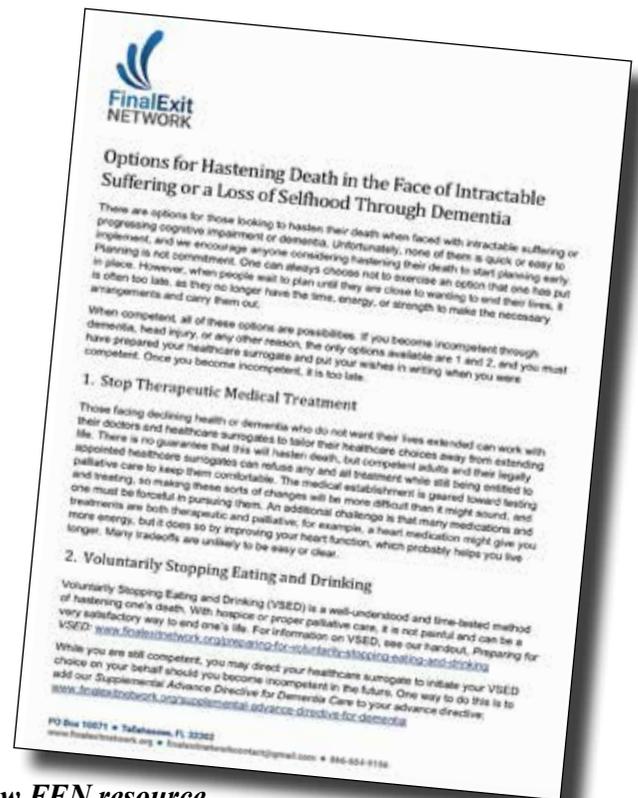
We plan to address the first problem, finding a surrogate. But with this column, FEN wants to start a dialogue about being a surrogate. One possibility is to establish a “Surrogate Consultant” who will be available (at no cost to you) by phone or Zoom to discuss what questions you need to ask medical staff, inform you of options that exist, and ensure that you

know a patient’s legal rights.

The consultant would not tell you what to do, but would be sure you have any information available to help make an informed decision.

Equally important, the consultant could intervene if the hospital or doctor refuses to comply with a legal surrogate decision. This may include coordinating with our FEN attorney – again, with no cost to you.

Is this something you would find helpful? Please see the box below left on how to give us feedback on your experiences as a surrogate, and whether you would find consultant services to be an important member benefit.



New FEN resource

Options for hastening death

FEN has just created a new handout, *Options for Hastening Death in the Face of Intractable Suffering or a Loss of Selfhood Through Dementia*.

This is information our coordinators provide regularly, and we’re kicking ourselves that we didn’t think to turn it into a handout sooner. We could have saved countless callers from hand cramps while they scribbled pages of notes.

It is a simple, straightforward summary of the paths currently available for peaceful self-deliverance, and it can be downloaded from our website:

www.finalexitnetwork.org/six-options-for-hastening-death/

We would like to hear about your experiences and how best we can help. We will be sending an email to members asking for your input. If you prefer to contact us now, please email me at jlandis10@aol.com or write us at:
Surrogate Consultant
Final Exit Network
P.O. Box 10071
Tallahassee, FL 32302
Tell us about any experiences you had or are having as a surrogate – and any tough times getting a patient’s wishes to be followed.

‘Maybe some good will come out of this, but I’m really sorry the whole thing happened ... especially for my father. He was tortured at the end.’



CRUEL DEATH

HEARTLESS (BUT POSITIVE?) AFTERMATH

By Jay Niver, FEN Editor

Barbara Mancini lived a nightmare. Because of it, North Carolina is three steps closer to gaining right-to-die legislation.

It’s a case of good coming from bad – but Mancini wishes there had been no chance for a “silver lining.”

Her father, 93-year-old Joe Yourshaw, suffered a horrific death against his wishes in 2013 – after taking every conceivable step to die peacefully in his Pottsville, Pa., home.

Mancini and her family endured a year’s bogus prosecution for her alleged assistance in a suicide. It made national news, including a *60 Minutes* segment with Anderson Cooper.

Ed Tiryakian, a retired investment banker with a law degree, was watching in his North Carolina home.

“I was so shocked and moved and horrified by this story,” he recalls. “This WW II veteran made it absolutely clear what he wanted for the end of his life ... and that poor man died fearful for his daughter’s arrest. I was so angry at what she went through.”

Mancini had handed her father a small vial of prescribed morphine at his request, and he drank it shortly before a home hospice nurse arrived. Then Joe’s loving daughter made the tragic mistake of mentioning it to the nurse. She called her superiors, who summoned EMS and police.

When they arrived, Joe was forcibly taken to an emergency room; Barbara was arrested and taken into custody.

Joe died a horrible hospital death after five days of

‘I had different plans for my life. I will never work as a nurse again. It does a number on you.’

lifesaving measures he never wanted.

Charges against her were dropped after a year of excruciating torment – and almost universal public outcry against the sham prosecution that turned her life upside down.

“The collateral effects have been pretty severe,” she says. “It’s been very tough emotionally, and I don’t think I’ll ever get over that.”

Barbara spoke with FEN this fall via Zoom. More than six years after her ordeal (legally) ended, and after telling it countless times in speaking engagements and interviews, she still finds it difficult to recount.

“I had different plans for my life. I will never work as a nurse again. It does a number on you,” she says. “I had an opportunity to bring injustices into the public consciousness, and I’m very glad I did that.

“But, boy, I wish this had never happened –

CRUEL continued on next page

especially for my father. He was tortured at the end. Absolutely tortured. And he did everything he was supposed to do to prevent that from happening.

“This really riles me up, that you can go through all these steps, have the conversations about your values and your goals for care, and it’s *written* down! Then, to have people in positions of power come and say, ‘Nope, that’s not gonna happen.’”

Ed Tiryakian was also riled up. He formed a nonprofit advocacy group, Dying Right NC, to pursue Medical Aid in Dying (MAiD) legislation in his native state.

Bills have been filed in three legislative sessions, and the last one (in 2019) boasted bi-partisan sponsorship for the first time. In notoriously “red” North Carolina, H.B. 879 (*End of Life Option Act*) was co-sponsored by two powerful Republicans as well as the usual Democrats.

Tiryakian is a dynamo who (before COVID) spent as much time in the NC Statehouse as some elected reps. He pretty much funds the cause out of his own pocket.

“I would not be doing what I am right now had it not been for Barbara’s story,” he says. “I decided that the laws and practices that had tripped her up cannot stand anywhere in America – and I set out to make sure that, at least in North Carolina, we’d pass a law making her nightmare something never repeated.”

Barbara Mancini sought no spotlight when she was thrust into the maelstrom surrounding her father’s death. Fact is, she was a reserved, private person and E.R. nurse.

She was also a devoted, adoring daughter who wanted to help Joe achieve the exit he planned.

“I totally get that a lot of these situations are not black-and-white,” Mancini says, “but my goodness! When you have people not even pretending to honor a document, it



Ed Tiryakian



Barbara Mancini still gets angry about a nightmare experience with hospice, her dad’s painful death, and her persecution by an abusive justice system.

should scare everybody.”

She emerged from the experience focused on three critical issues: hospice care, laws against assisted suicide, and the criminal justice system. She was abused by all and wanted to spread the word.

Mancini’s father-daughter-family ordeal was triggered when she mentioned morphine to the hospice nurse. In retrospect, is she glad it may spur reform?

She replies without hesitation, “I wish I had never said anything that day.”

The case against her eventually disclosed substantial hospice failure on many levels. Her own subsequent sleuthing revealed: All hospices are not created equal.

“My biggest regret is that I didn’t do more to research hospice care,” she confesses.

Mancini adds, “There’s a heightened awareness about criminal justice issues everywhere now. Things have been exposed about how prosecutors and police scam the system.”

Since joining the RTD cause (albeit regretfully), she has added a fourth plank to her reform platform: “the politics around how people are allowed to die ... This journey has been

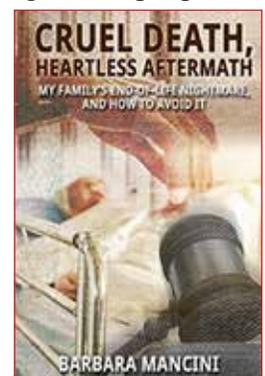
a real education for me, especially when you talk about legislation being passed,” she explains.

Mancini testifies before state lawmakers who are considering MAiD. She’s had some eye-opening revelations, particularly in Connecticut.

“I was supposed to be 18th to speak,” she recalls. “Everybody was given three minutes to say their piece. The hearing started at 9 a.m., and I finally got to testify at 9:30 that night ...

“They were basically filibustering. When people opposed to aid-in-dying spoke, committee members who agreed with them would ask question after question. A three-minute testimony got drawn out to sometimes 60 minutes.

“The tactic is to stop a bill before it ever gets out of committee, if it even gets that far.”



Hospice, too, can leave dying patients vulnerable

FROM EXECUTIVE DIRECTOR MARY EWERT



A 2018 *New York Times* column recently came to my attention. It told the story of a woman whose father, in home hospice care, died in pain. Her critique of the home hospice system, particularly its inability at times to relieve a patient's pain, stirred memories.

In 2001, I watched my father's decline with prostate cancer that eventually spread to his bones. His hospice experience at home was adequate – until the final days when he was racked with pain.

Hospice staff, apparently stretched thin, were unable to send someone as my dad suffered. My stepmom and I (neither of us medically trained) could not manage to administer pain medication in pill form to a patient who could no longer swallow.

FEN is committed to empowering those who refuse vulnerability, those who see no value in exhibiting 'true grit' at the end of their lives.

It was a heart-wrenching experience for all of us. I still reflect on that experience and wish I had been able to offer my dad a gentler death.

When, in 2006, my husband, Craig, contracted ALS, I looked with horror on the end game we might both experience. He gasping for breath, me watching helplessly, again traumatized by not being able to offer relief to my loved one.

Craig tried to initiate a discussion with his neurologist about how the end would play out, but the doctor refused to talk about it. He then spoke with a hospice doctor who, while he understood my husband's fear, could not promise the merciful end my husband might choose before he entered the final stage.

Craig was a mathematician, not one to take nebulous assurances that most people don't suffer seriously. He successfully sought an aid-in-dying option and ended his life as he wished.

My memory of his ending is both warm and bittersweet, filled with memories of our time together, and thankfully lacking the trauma I felt when my father died.

My experiences are not unique. This edition of the FEN magazine has two other wrenching stories of failed hospice care. One is the cover story of Esta Asteroff's experience with her husband; the other is Barbara Mancini's tragic case with her father, which caused a national uproar (see page 4).

In our current system of dying, it is the patient who is vulnerable, at the mercy of a for-profit healthcare system and doctors who are cowed by laws restricting their ability to treat pain.

A New Zealand physician, explaining how he became a supporter of that nation's recently passed End of Life Choice Act, said he once believed that physicians would scientifically analyze symptoms and treat them as they emerged. But many years of watching patients die shattered his belief.

He concluded that when a doctor dismisses a patient's wishes, he or she is behaving in a paternalistic and condescending manner, making those dying with unbearable suffering a truly vulnerable group.

FEN is committed to empowering those who refuse vulnerability, those who see no value in exhibiting "true grit" at the end of their lives. That's why we continue to develop tools to put control in a dying person's hands, including our Supplemental Advance Directive for Dementia Care, and most recently the Surrogate Program to support healthcare agents as they advocate for those they represent (see page 2).

To carry out this essential work, FEN relies on contributions and bequests. Soon you will find FEN's annual appeal in your mailbox. I hope you are inspired to donate through our secure website (<https://finalexitnetwork.org/donate/make-a-donation/>).

We encourage those who are comfortable donating online to do so – it reduces staff processing time. Donations can also be mailed to FEN, PO Box 10071, Tallahassee, FL 32302.

You only die once. *FEN is here to make sure you have a choice in the matter.*



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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.



Gretchen, Belinda, and sister Laura (l-r) in 2016.

A TWIN'S TOUCHING TRIBUTE

Societal norms are shifting, and we are pleased to notice a growing number of families who are coming out of the shadows – not in a confessional way, but proudly – to share in obituaries and farewell notes their loved ones' choices to conclude their lives when ready.

This summer, having been educated by FEN Exit Guides, Belinda chose to hasten her death after years of debilitating illness. Gretchen, her twin sister, posted the following tribute on her Facebook page. Gretchen agreed to let us share it with you.

– Jay Niver, Editor

To Our Dear Friends,

My beautiful sister, our Belinda, passed to the other side a few weeks ago. She hastened her own passing in order to provide herself relief.

She survived 11 years on oxygen with dignity and courage, because she could not have her heart disease treated. She was a real fighter, a rebel against what is wrong with our world, lover of all things gentle and beautiful; her soul, the most loving and kind.

I miss her deeply and so does our family, the oldest (our father 96) and the youngest (our half sister, 26). She did not suffer; she went peacefully as in sleep. She had a joke, “They (the powers that be) keep you poor and miserable, and then they tell you that you can’t even leave!”

At the end, she took back her power, she did what she wanted. I am so proud of her. Her spirit has already been made known to some friends and family and I believe is alive and well, on the other side, where she is finally safe, off of oxygen, so beautiful again, and free.

My love to all, Gretchen

Derek Humphry – Lowrey Brown

Is suicide rational for elders who are not terminally ill?



Derek Humphry

FEN Advisory Board Chair

Nowdays it's fashionable to use euphemisms for elderly suicide, self-deliverance, and doctor-assisted suicide. Old age self-killing is now called the "completed life."

The arguments for and against are already laid out in dozens of articles and books, almost entirely by academics and physicians (see Google). Thus, I will summarize mine as a lay person:

For someone over 70 who has declining health and scant happiness, it is logical to end their life if they so wish. Each person must decide for themselves, not go with a trend or somebody else's persuasion.

Suicide is not a crime, nor is it such a disgrace as it was in older times, provided there is a reason. I think this reason for leaving life should not be sanctioned or advocated or practiced by groups.



Life is a personal responsibility; thus, whether a person hangs on to the inevitable end depends on individual medical circumstances, personal ethics, and each person's quality-of-life values.

But to have that choice in what I call "self-deliverance" requires thinking and planning ahead. Many persons do not do so until it is too late, or they are trapped in a nursing home or hospital.

It is a step too far to offer assisted-dying to the elderly or mentally ill. Outsiders cannot see into the minds of such requesters – what is their motive?

Over my 40 years' involvement in the movement for choices in dying (personal and lawful), scores of people have begged me for help to die, and I had no alternative in their particular circumstances but to say, "Sorry, but you've left it too late."

Too many people want to lean on you instead of deciding for themselves in advance.

I do not think that right-to-die organizations should program themselves to aid those with what is called "completed lives." Nowdays we have broad public acceptance of assisted dying for those who are end-stage terminally ill and the hopelessly degeneratively ill – provided it is their rational choice.

It is a step too far to offer assisted dying to the elderly or mentally ill. Outsiders cannot see into the minds of such requesters – what is their motive? Is their thinking balanced? What does their family think? What is the true state of their finances and their financial legacy? Especially in such a litigious country as America, potential legal problems abound.

If a person no longer wishes to live, they must end it themselves, preferably by planning ahead and advising close family and friends of their intentions so as to reduce the shock when it occurs.

(Editor's note: Derek Humphry is 90 years old.)

Point ← → Counterpoint



Lowrey Brown
FEN Client Services Director

Society has come a long way toward understanding and respecting the idea that competent adults facing a terminal illness with less than six months to live should have access to Medical Aid in Dying (MAiD). However, the widespread understanding and respect for MAiD does not often translate into understanding and respect for those who wish to hasten their death on their own, outside the medical establishment.

Society does not prepare individuals or their families for the possibility of a self-chosen death without sanctioned medical support. No one teaches us about this

option in health education. Health insurance companies aren't sending us brochures advising us to consider what quality of life we find acceptable and offering to help us plan to avoid a future we find unacceptable.

Society fails to prepare us to even consider, let alone achieve, our own deaths when we are ready. That some of us are prepared is, in very large part, a tribute to Derek himself, and I raise a glass in his direction.

That so many of us are not prepared, however, is not a reflection of willful carelessness. It is a reflection of our society, in which it is no surprise that a bereaved 80-year-old might look up after a lifetime of living and years of caring for an ailing spouse, realize that she is squarely in the cross-hairs of a nursing home, and – for the first time in her life, think – “Help! How do I get out?”

I disagree that all FEN should do for such people is point them to a book and shake our heads, that they should have thought about it earlier.

There is a lot of medical ground between comfortable health and terminally ill. In my experience, individuals considering ending their lives in the near future are rarely comfortably healthy. Limitations from pain and debility are often part of what prompt people to consider their lives to be “complete.”

FEN has never required applicants for Guide support to have a terminal illness, and we recognize that a constellation of medical conditions – such as painful arthritis, growing deafness, and fading eyesight – can seriously degrade quality of life.

We are also conducting research to better understand the psychosocial conditions that matter most to people who consider ending their lives, as we recognize that the human experience goes far beyond the body.

We cannot see into the minds of any who request

our services, but we talk to them and to their families, we ask them questions, and we listen to what they have to say.

FEN provides education and a compassionate presence under the protection of the First Amendment. Though our volunteers always face the risk of baseless prosecution, they accept the risk, knowing that FEN stands behind them.

Until society acknowledges that many of us are living longer than we want – and takes practical and effective steps to prepare and support people to consider hastening their deaths – I hope FEN will continue to counsel and guide (for those who meet our criteria) people who, after careful consideration, have decided their lives are complete.

Society has abandoned them at such a critical crossroads in their lives.

Derek's Reply: Your response is well argued, mostly agreed, but does not convince me when it comes down to the actual face-to-face help.

Would FEN send two Guides to help a person die who has a completed life? A raft of personal ethics, conscience and legal risks comes to mind for the visitors.

As I said, life is a personal responsibility.

(Editor's note: This discussion first took place on the [Good Death Society Blog](#) and includes reader comments.)



Massachusetts and New York are well on their way. I'm not going to say they'll pass this year or next, but they could. The calculus is almost there, where we need it to be.

– Peg Sandeen



As executive director of the [Death with Dignity National Center](#) (DwD), Peg Sandeen knows more about the right to die and states' efforts to secure aid in dying than almost anyone in America. She sat down recently with FEN for a Zoom meeting to discuss the state of the RTD movement, what lies ahead, and her own personal involvement.

– Jay Niver, Editor

She was 27, “just a kid,” when her dying husband asked her to kill him. He was only 33. She didn’t do it, but that tragic experience (“it wasn’t a pretty ending”) helped Peg Sandeen chart her life’s direction.

Her mother was a hospice nurse, which provided Peg an early lens on death and dying. She’s been working with DwD for the past 15 years.

She is optimistic about more states passing laws to let dying people exit peacefully on their own terms, with the “dignity” encased in DwD’s name. The turning point, she says, came when California passed its bill in 2015, propelled by the heart-rending case of Brittany Maynard, which gripped the nation.

Before then, Sandeen notes, “There was Oregon, Washington, and Vermont, those *libertarian outposts*, those *radicals* in the West and the East.” Now one in five Americans has legal access to Medical Aid in Dying (MAiD), in nine states and the District of Columbia.

“Now we’re seeing Kansas consider a death-with-dignity bill, an (advocacy) organization in

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North Carolina, and Texas having a movement, and Ohio has a movement,” she says. “It’s really mainstream legislators, ‘Middle America’ starting to think about death with dignity as a viable option.”

Help is also coming from an unlikely source: the pandemic.

“I absolutely believe that COVID has caused people to look more at end-of-life issues, and that’s positive,” Sandeen says. “I think we’ll see a majority of Americans who have written or rewritten their Advance Directives. There may be some astounding numbers come out regarding end-of-life planning.”

But there is a cloud on the horizon: “We’re concerned about the (U.S. Supreme) court. Certainly, the balance of the court has shifted, and a number of issues could face difficulty as a result of it,” she opines. “If the court takes on *Roe (v. Wade)*, it’s hard to know what this court may be interested in tackling ... that’s a somewhat scary unknown.”

In the states – where the RTD issue is fought and decided – Sandeen sees the same formidable opponents that have fought the movement forever: the Catholic Church and right-to-life forces.



The latter have always wielded undue influence (usually with GOP legislators), equating an unborn fetus with a competent, terminally ill adult.

The Catholic Church has historically out-spent all RTD opponents, despite the fact that polls show Catholics support aid in dying. The church has suffered immense financial blows to settle pedophilia lawsuits, but Sandeen says it hasn’t impacted their ability to lobby against MAiD.

“If I look back to 2012 in Massachusetts, the archdiocese of greater Boston was bankrupt ... and they still found \$7 million to go against the state death-with-dignity bill,” she explained. “I hear, ‘The Catholic church doesn’t have the sway,’ but the reality is that an archbishop or a priest or someone else picks up the phone and makes one call and a bill

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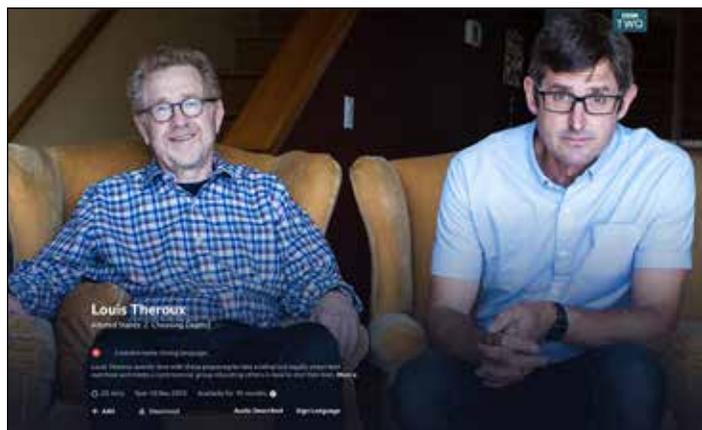
BBC documentary features FEN at work

In 2018, well-known documentary filmmaker Louis Theroux came to the American West Coast to examine the thorny legal and ethical issues around Medical Aid in Dying (MAiD).

Working with the British Broadcasting Corporation, he followed three terminally ill people who hoped to die on their own terms. Two sought help under California's then-new End of Life Option Act, and the third was an Oregon woman who did not qualify for MAiD but did meet FEN's criteria for Exit Guide support.

Theroux attended as FEN Exit Guides worked with her, and he saw a demonstration of her do-it-yourself exit apparatus.

The episode, "Choosing Death," was part of



FEN Board President Brian Ruder (l) with Louis Theroux on the set of "Choosing Death," the BBC film now available in the U.S.

Theroux's *Altered States* documentary series.

It is now available to watch in the United States through HBO Max. Those who aren't subscribers can still enjoy watching Exit Guides at work by signing up for a free 7-day trial at www.hbomax.com

CHAT *continued from prior page*

can be stopped."

One traditional source of obstruction is fading.

"Doctors are no longer a legitimate face of opposition," says Sandeen, "and that is a tremendous kind of political change."

The American Medical Association hasn't budged at a national level, but state groups of healthcare providers – doctors, nurses, and others – are no longer opposing MAiD. Most don't endorse it, but they are adopting a neutral stance.

That should make it easier to pass more aid-in-dying legislation. Sandeen believes there is also a growing recognition of end-of-life issues.

"As the boomers age and more people come to understand the dying process, and what changes in modern medicine have made for how we die, more people will come to understand that this is an important issue," she says.

Still, there are ominous challenges on the horizon.

The "Oregon model" of planned, dignified death for terminally ill people has been the U.S. template for 23 years. But it excludes many thousands of suffering Americans who can't access it for one of two reasons:

1) They are impaired by dementia, and every law requires the patient requesting help to be of sound mind; or

2) People with intractable illness (ALS, MS, Parkinson's, or other diseases) cannot get relief because their condition may last for years – they are not "terminally ill." Their quality of life may be unbearable, but there is no remedy under existing MAiD laws.

DwD opposes liberalizing the RTD criteria, though they don't want safeguards to be a barrier to access. Waiting periods, witnesses, and paperwork requirements are some of the logistical hurdles that

need to be minimized, according to Sandeen.

She says DwD works closely to

support state organizations: "Our partnership with state groups is important. You're not going to see us saying, 'You have to do this, you have to sign this, you have to agree with this.' I really believe in the local work that's being done."

Sandeen says she also appreciates a growing relationship with Final Exit Network. "I'm very pleased that we are closer together and working more in sync ...

"I think of you sometimes as librarians, people who provide information. Some people want to ban books, but it's just a conduit of information. And I think that's a good thing."



One man's view: MAiD or SID?

RTD laws fail if you can't DIY

By Leonard Levenson, FEN member

As a relatively healthy 79-year-old married man whose mother, 80, wasted away over a seven-year period due to Alzheimer's, I have a confirmed genetic profile that increases my chances of a similar fate.

I've witnessed in others much pain and suffering, both physical and emotional, due to disease, injury, and decline. I've personally known of three tragic suicides.

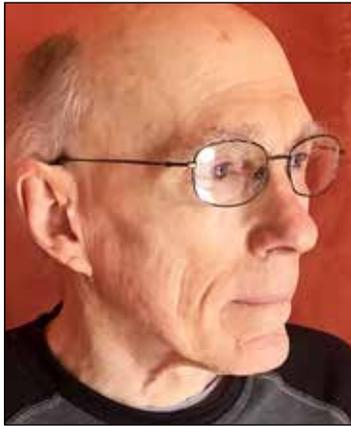
For these reasons, I've expressed to loved ones how I wish to die. They are both understanding and accepting:

- I will be surrounded by those who feel comfortable enough to be with me when the time comes;

- Together, we will celebrate the extraordinary gift of life itself; we will talk and take joy in the fact that we shared so much;

- We will say our farewells;

- Then, I will take an appropriate elixir that will take me gently out of existence with a smile and a sheen on my face.



Leonard Levenson

Such an ending would be a satisfying one to my life's story. When such a time arrives, I would hope that the laws had changed to allow me to use Medical Aid in Dying (MAiD) – even if I am unable to do so myself.

Every U.S. MAiD law requires the patient to trigger his or her own demise. But do-it-yourself (DIY) doesn't work for those who are unable to do it themselves.

I'm not optimistic that my wish will be legally granted, and this brings a degree of anxiety and stress into my life.

It should be otherwise.

Because the laws do not now allow for my desired ending, I may be forced to execute a SID, or "Self Inflicted Death." By necessity, it will have to be carried out away from loved ones.

If my life's quality diminishes to the point

In my world view, there is no moral justification for others to deny me the liberty to pursue my desired kind of death.

where living becomes unacceptable to me while I still possess the mental and physical capacity to kill myself, I will. In other words, unless the laws are altered by people to allow for my desired peaceful, humanitarian end, my exit will come about by a premature, self-inflicted, violent act, committed alone, angry, and afraid. As a result, I'll be another statistical suicide, leaving my family in pain.

I should not have to resort to this. In my world view, there is no moral justification for others to deny me the liberty to pursue my desired kind of death.

I hope to be able to continue to participate in our end-of-life movement for years to come. I don't want any senior who is suffering a diminished life to end his or her life alone, violently by SID.

What I do want is for the laws to be changed to allow persons to be able to end their lives on their terms, and to be able to acquire the means to do so, even if they require help from someone else.

No one should have to resort to a gun or a rope because they fear such help will never come.

Everyone should be able to be surrounded by others as he or she approaches a warm-hearted, final exit. Under such circumstance, there is a possibility that one may decide to remain in life a little longer, rather than to forever leave it.

That final decision should be solely the individual's right.

The author is correct that MAiD laws and laws against assisting a suicide mean that people choosing to end their lives must perform the action themselves.

However, as those serving in the Exit Guide Program know, that does not mean you have to be alone or resort to ropes or guns. Our guides work with individuals to plan gentle and peaceful exits using inert gas. Loved ones and guides may accompany an individual who chooses to exit, celebrating (as Mr. Levenson rightly says) the extraordinary gift of life.

– Lowrey Brown, FEN Client Services Director

co·or·di·nate \ kō-'ōr-də-, nāt \
v. to make many things work
effectively as a whole –
*hugely understates what a FEN
coordinator accomplishes*

Coordinator is FEN clients' critical 1st contact

Editor's note: The following account is by guest contributor Susie Y., a FEN volunteer who serves in the vital role of coordinator.

Of all the important roles filled by volunteers for Final Exit Network, the coordinator is the first line of contact for all inquiries. When a person contacts FEN via the website or answering service, they can usually expect a call from a FEN coordinator within a day or two, thus beginning a unique relationship that may be fleeting – or may be long-term.

In my role as coordinator, my job is to listen discerningly, field questions, provide information, encourage, support, brainstorm, and try to help in any way I can. It's not for me to judge as I process personal stories from those who want to have control over a peaceful ending.

The reasons for making that first call to FEN are as varied as the people who initiate it. It usually involves chronic suffering or a recent, grim diagnosis. Some call on behalf of themselves, a spouse or partner, elderly parents, or occasionally an adult child. Some are desperate for an immediate solution to their predicament; others just want information for "some day."

Some are planners, and some have made no plans at all, but everyone wants to know their options.



It's not exactly a friendship, and yet it can be oddly much more than that. We may start out as strangers, but a unique bond is quickly formed.

Knowledge is power, and having autonomy over one's end of life takes foresight and planning. We are not a crisis organization and do not operate as such.

As coordinator, I listen carefully to people's stories. Often, it is obvious what they want, and we quickly get right into it. I go through the FEN protocol of what they need to do to initiate an application for services. This involves helping them figure out what paperwork to submit, followed by an interview by a different FEN volunteer.

Then their paperwork goes to the Medical Evaluation Committee, where three physicians will review all the information and determine whether the applicant qualifies for provisional approval.

If approved, a Senior Guide is assigned to work with the client going forward. This all sounds straightforward, but the reality is that it can be quite a rigorous process that involves many phone calls and waiting for weeks to pull everything together.

Many callers are not seeking exit services. Some people just want to know more about FEN, like how to become a member or how to make a donation.

... the reality is that it can be quite a rigorous process that involves many phone calls and waiting for weeks to pull everything together.

COORDINATE *continued on next page*

Good Endings Book Club



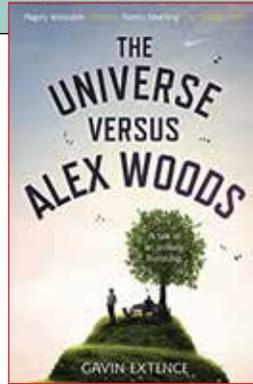
The Universe Versus Alex Woods by Gavin Extence

Reviewed by Jim Moschella

This is a coming-of-age novel without sex.

Instead, the 17-year-old protagonist tells his tale of accepting a friend's desire for self-deliverance after receiving a diagnosis of an incurable degenerative disease.

Despite this theme, the



novel is full of laughs, since it's told with a young adult's mix of sarcasm and naiveté.

Also, the narrator's attitudes are the result of his experiences growing up after being hit by a meteor when he was 10. While that part may seem a little far-fetched, the events that follow are all very plausible and told with plenty of humor.

Our hero has a variety of physical and emotional scars from the meteor that were brought on by both his tarot-reading mother's obsessive attempts to protect him, and the inability of his classmates to accept someone who is different. But these scars enable him to develop the friendship with the older gentleman and to be sure in the knowledge that he is doing the right thing by helping his friend, regardless of the resulting international search for the two of them.

The death act is described somberly, but even then we get the zinger: "At your funeral, would you rather have the pall-bearer who keeps a steady hand or the one who is so overcome with grief that he drops the coffin?"

Overall, it's a fun affirmation of what we do!

COORDINATE *continued from prior page*

Some want to know how we can help someone diagnosed with early-stage dementia.

In recent months, there have been calls from people who are anxious about catching COVID-19; they often just want to talk and vent, and we share similar concerns. There also are the worries about an elderly parent who has "had enough." Some don't want to go through our protocol of collecting their medical records, but would still like information.

Many callers are asking questions they don't want to ask and may have considerable anxiety around the potential answers. Regardless of the circumstances, I try to "meet them where they are" and do what I can to address their needs.

I have talked to some of the nicest people as coordinator. I may talk to some only once because that

Susie Y. joined the Hemlock Society more than 30 years ago, "when my dad was sick with cancer and I had my first baby, so I have long been interested in death-with-dignity issues."

Her husband also volunteers with FEN. They live in New Hampshire and have three grown children.

... I am thanked repeatedly for listening, talking, helping, and not judging.

is all they need. Others call me periodically to check in with their health updates.

A few have even called to check in to see how I'm doing. Sometimes I have the opportunity to talk to spouses, siblings, adult children, and extended family.

The coordinator and client develop an unusual relationship. It's not exactly a friendship, and yet it can be oddly much more than that. We may start out as strangers, but a unique bond is quickly formed. After all, we "met" at one of the most difficult times – when a person is vulnerable and asking for help in facing the hardest decisions ahead. Our conversations are profound as we explore heavy thoughts that can't be shared with just anyone.

Pretty much, without exception, I am thanked repeatedly for listening, talking, helping, and not judging. I care deeply about these callers; I think about them a lot and wish them well.

Coordinators connect to callers through our shared humanity, and we extend our compassion at a most crucial time.

3

THE BACK PAGE

A COMPENDIUM OF RIGHT-TO-DIE WORLD NEWS

New Zealand

New Zealanders endorsed the right to die but not to get high when they voted in separate October referendums. Voters approved the End of Life Choice Act by 65 percent, but fewer than 50 percent agreed that recreational marijuana should be legal.

The new law will take effect in November 2021. It allows for conventional MAiD, when a doctor provides the lethal means for a patient to end their own life, but it also extends to “voluntary euthanasia,” when a physician performs an intervention to carry out the patient’s request to end their life through drugs or an injection.

New Zealand joins The Netherlands, Belgium, Luxembourg, and Colombia among the few nations that have legalized euthanasia.

France

The terminally ill Frenchman who was blocked from live-streaming his own death on Facebook has now accepted palliative care and backed down on a vow to starve.

Alain Cocq, 57, had twice attempted Voluntarily Stopping Eating and Drinking (VSouED), but decided in October he did not have the “capacity for the fight any more.”

His case has been closely watched in France, sparking debates over right-to-die legislation.

In July, he appealed to President Emmanuel Macron, describing his “extremely violent suffering” and asking for permission to die “with dignity.”

In late September, Cocq announced he had finished his “last meal” and would refuse food, drink, and medicine until he died, but Facebook on the same day blocked his plan to stream himself slowly dying.

England

● New pandemic lockdown rules in England that place restrictions on leaving home without a reasonable excuse will not apply to those who want to die in Switzerland.

MP Matt Hancock told MPs

that seeking an assisted death abroad counted as a “reasonable excuse.” He also stressed that it remains a criminal offence to encourage or assist the death of another person.

He was replying to Conservative MP Andrew Mitchell, who said new coronavirus regulations could “deter” terminally ill people from travelling to Switzerland for an assisted death.

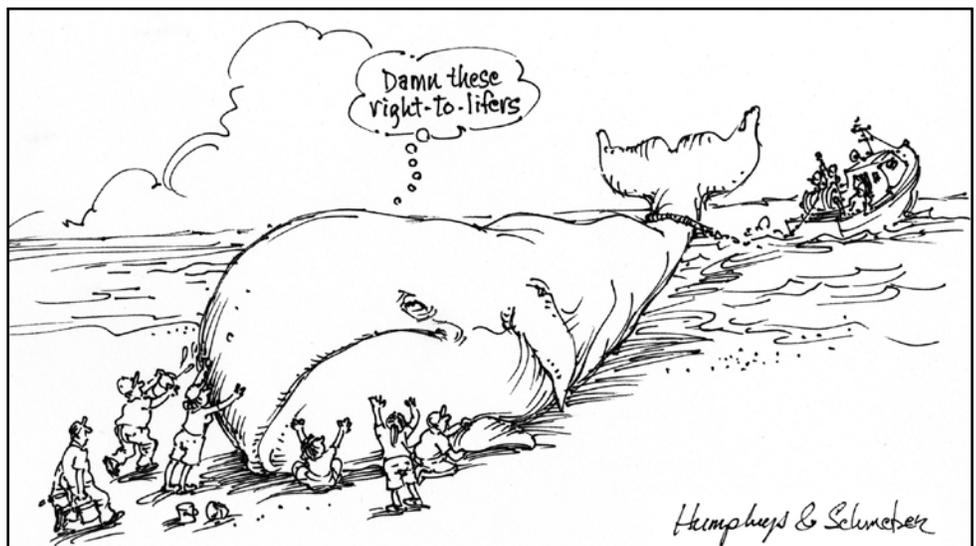
● The largest-ever survey of English doctors’ views on assisted-dying shows a historic shift for greater end-of-life choice.

The British Medical Association’s (BMA) first-ever survey of members’ views on the topic has found that doctors are in support of it and want the BMA to drop its official policy of opposition to a change in the law. Nearly 29,000 physicians responded, and 40 percent said the BMA should support a change in the law; 21 percent said they should take a neutral position; just 33% thought the BMA should maintain its opposition.

Ireland

Debate is heating up after Dying with Dignity Bill 2020 passed the second stage in the Dáil and moves to committee for further contentious scrutiny.

In addition to customary MAiD, the proposed legislation would permit full-blown euthanasia if it is impossible or inappropriate for the terminally ill person to self-administer. A doctor could prescribe, provide, and administer the drug directly.



RTD, FEN stalwart Coppens steps away after 30+ years

Hello everyone,

This is my retirement letter, something I have been thinking about for some time. It is with deep gratitude that I am writing to all of you, some I have known for years, some I have known for a while and some I have crossed paths with.

Wonderful people!

I would like to share my last “face to face” case with you, as a Senior Guide. I had the amazing privilege to be present and witness a great love.

It was a while ago that I met this sweet couple. They lived in a tiny, brightly decorated, neat little home.

He presented as a striking figure, tall, attractive man, diagnosed with early Alzheimer’s. A former biker. She was a beautiful, petite woman. They had found each other some time ago, when they both immediately recognized each other as soul mates.

They were clearly deeply in love with each other, experiencing great pleasure in each other’s company. She told me she gladly would take care of him as his disease overtook him. But he clearly did not want this; instead, he wished to go before declining further.

It was time to go, however painful that was for both!

He was ready during the first visit, but she had no support person present with her during this visit. We scheduled another visit, when an old friend of theirs could come and be a support to both, but mostly for her after his death.

Two weeks later, I joined them again. When it was time for him to lay down, I suggested they say goodbye one last time.

Both hugged. He held her tight to his body, cupping her close to him, while she stood on her toes, both kissing through their masks.

I suggested they remove their masks, and they kissed one last time. Such love and pain all in this one last kiss!

He died being held by her, this tiny loving woman curled up against his side, waves of grief racking her body and heart. He died a big man held by love.

Thank you!

I wish you well, keep doing this very important work, you are all amazing!

Myriam

Myriam Coppens was a quiet, unassuming giant of the right-to-die movement for more than 30 years, and she blessed FEN as an Exit Guide since 2008. She started the Portland Hemlock Society in 1989 and testified for Oregon’s seminal Death With Dignity law, and labored tirelessly as an advocate for end-of-life choice. She worked passionately with countless FEN clients whom she supported in achieving a peaceful, dignified death.

“Myriam was the first Guide I worked with, and she took me under her wing as I learned the ropes ... I remember one visit watching her calmly navigate some very intense family dynamics; I navigated that visit with eyes wide and mouth closed. There was no one better to teach me that guiding is a lot more than tanks and tubing.”

– Lowrey Brown, FEN Client Services Director