FinalExit NETWORK

The Human Right To A Death With Dignity

IN THIS ISSUE

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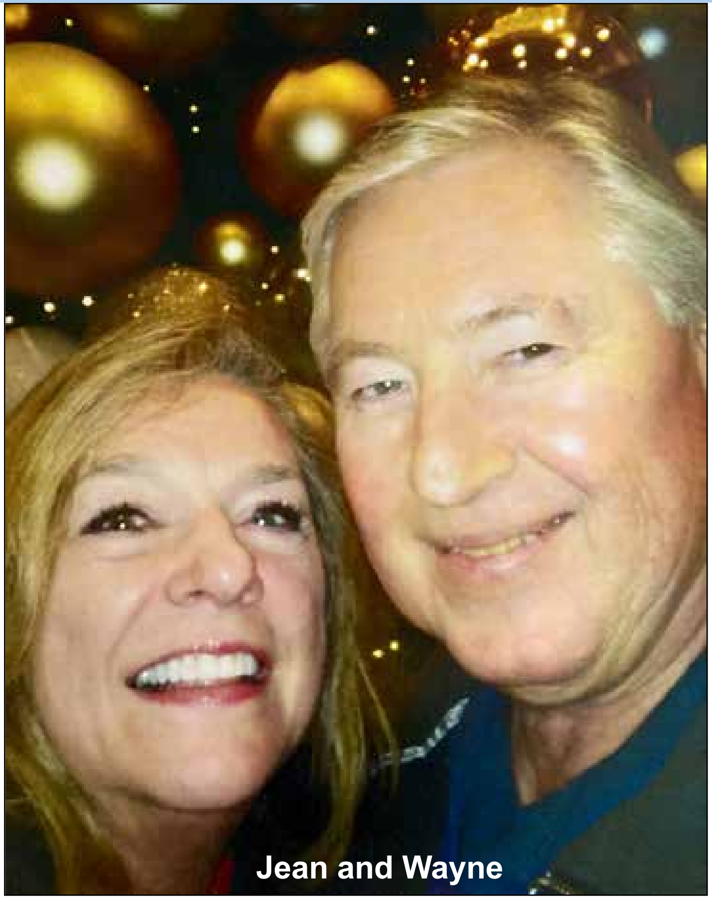
No glitter at the end

Before he died, Wayne Marquardt made no end-of-life plans. His fiancée Jean and brother Kevin paid an agonizing price.

By Kevin Bradley, FEN Member


Jean and Wayne

Wayne and I got COVID around the same time. He was 10 years older and had multiple underlying health issues, so it wasn't a surprise that he was affected much more than I. The coroner's certificate says the primary cause of death was pneumonia due to COVID, but it also lists coronary artery disease, hypertension (high blood pressure), hyperlipidemia (high cholesterol), and gout.

The biggest surprise was that his claustrophobia, which I was not aware of, ended up being more significant than I could have imagined.

Wayne's first symptoms appeared Tuesday, Nov. 30. He initially thought he had a sinus infection. The next day, he was coughing and thought he might have bronchitis. A week later, he was admitted to the hospital with COVID pneumonia. He transferred to the ICU two days later, reportedly just to "keep a closer watch" on his blood oxygen level.

That's when I learned that he did not have an advance healthcare directive or medical power of attorney. The fact that he was in the ICU was an indication to me that his condition might be worse than he was admitting (or maybe than the hospital staff was telling him).

I offered to create a POA for his fiancée, Jean, to take to the hospital for Wayne to sign. Without it, she wouldn't have any legal say in his treatment, and I knew Wayne didn't want that. I created the medical POA over the weekend and emailed it to Jean Monday afternoon to review. We were still expecting Wayne to be sent home with arrangements to have oxygen. The POA was "just in case."

On Monday night, because Wayne didn't seem to know much about his diagnosis or treatment plan, I filled out a request form to get access to his "medical portal" to see his medical charts and clinical notes. I planned to bring the form to Wayne the next day to get

NO GLITTER *continued on page 2*

> ***The attending physician arrived and insisted that Wayne had told him to do 'everything possible,' which, to the doctor, meant intubate.*** **I was stunned.**

NO GLITTER *continued from page 1*

his signature on both documents.

On Tuesday morning, Jean spoke with Wayne on the phone. He thought he was in a grocery store.

The nurse called it "COVID delirium," and we assumed it was temporary. My wife, Melanie, and I drove to the hospital to meet up with Jean. The hospital is an hour's drive from our home.

Since we thought it would be just a brief visit, Melanie waited in the car while Jean and I went to get his signature on each form – only to learn that he had been fully sedated. The delirium had apparently gotten worse and amplified his claustrophobia, resulting in a belligerent refusal to wear the CPAP (continuous positive air pressure) mask necessary to keep him alive.

In his delirium, Wayne didn't understand the importance of it. He just knew he wanted it off. The only way to keep it on him was to render him unconscious.

We were too late to get his signature.

From Bad to Worse

Jean and I were allowed to see Wayne from the other side of a glass door. He made no indication that he knew we were there. We were informed that a new, mechanized CPAP had been set to full flow, but his blood oxygen level was still dropping.

WILD BROs – Kevin (l) and Wayne chow down at a Minnesota Wild hockey game.

The attending physician wanted to intubate Wayne and transfer him to a larger hospital with more on-site specialists, but no ICU beds were available anywhere in the state, so Wayne was first on the waiting list.

I knew that many intubated COVID patients did not survive, but I was unable to think clearly enough to argue with any conviction. We were sent home to wait for a call to notify us which hospital could take him.

The next morning, an intensivist (specialist in intensive care) from one of the larger hospitals called to say he had seen Wayne's medical chart and disagreed with the intubation and transfer plan. According to the intensivist, even if Wayne recovered from both COVID and intubation (a 10 percent chance at best), he would need a permanent tracheotomy due to the irreparable damage already done.

Blood tests indicated he had also suffered an acute kidney injury, so there was a good chance he would soon be on dialysis. His delirium-fueled belligerence indicated some cognitive decline, which had most likely continued since his blood oxygen levels were still dropping. He likely would need continual nursing care.

We were shocked by this news and how fast Wayne's health had gone downhill.

The intensivist advised going back to the hospital to say our final goodbyes and offered to arrange for a "compassionate visit." When we arrived at the hospital, however, the receptionist and nursing staff knew nothing about a visit. After telling the receptionist about our conversation with the intensivist, we were allowed to meet with the attending physician in an ICU waiting area. We were not yet allowed to be with Wayne. We were kept waiting for about an hour before the doctor came to speak with us.

Jean and I had agreed that Wayne would not want to be kept alive with machines. She specifically recalled a recent conversation with him about possible nursing care in years ahead, and he said, "I don't want to watch the world pass me by."

The attending physician arrived and insisted that Wayne had told him to do "everything possible," which, to the doctor, meant intubate. *I was stunned.*

Call in the Lawyers

After several minutes of heated discussion, the physician informed us that he had already contacted the hospital's legal department, which arranged for the ethics committee to meet, although no one could tell us when that would be.

Wayne's care had been completely removed from our hands. We felt powerless. By then, it was late

The receptionist called a nurse supervisor, who arrived at the ICU prepared to have security escort us off the premises.

afternoon, so the three of us briefly saw Wayne again from the other side of the glass door and went to Jean's house to wait.

After another two hours of waiting and hearing nothing, we learned that there was a weather advisory with possible tornado activity. Since we didn't know when we would hear back from the ethics committee, Melanie and I decided to go home before the storm hit. We arrived just as the wind suddenly grew stronger with torrential rainfall.

The garage door was still opening when the attending physician called to say the ethics committee had agreed to defer to the family. He also said that Wayne's blood oxygen level and blood pressure were suddenly dropping, so we should get there as soon as possible.

I called Jean to share what I had just learned, and she immediately went back to the hospital. Melanie and I were forced to wait 45 minutes for the worst of the storm to pass, then we drove the hour back to the hospital for the third time in two days. It was well into the evening when Melanie and I arrived, so a different receptionist was on duty. She said hospital policy allowed only two visitors in the building, and since Jean was already there, one of us had to wait in the car.

This was the first we'd heard of that policy, and we were surprised since all three of us were allowed to "visit" Wayne earlier that day. I was not about to leave Melanie sitting alone for who knew how long during a severe storm – *yet I had to get to Wayne.* In my urgency, I ignored the receptionist and went upstairs to the ICU, taking Melanie with me.

The receptionist called a nurse supervisor, who arrived at the ICU prepared to have security escort us off the premises. As I forged ahead to get to my brother, Melanie told the nurse supervisor that all three of us had been in the ICU just a few hours earlier after being promised a compassionate visit that didn't happen, and that the ethics committee overruled the attending physician, who then urged us to come back to the hospital right away. The supervisor eventually agreed to let Melanie stay in the ICU waiting room while Jean and I were at Wayne's bedside.

We had only been in Wayne's room a short time when yet another physician arrived and wanted to speak with us (there had been a shift change for doctors as well). This was our third doctor of the day.

Bracing myself for yet another confrontation, I was greatly relieved when he told us in the waiting room that he agreed with the intensivist. His reassurance that we were making the right decisions for Wayne gave us tremendous peace of mind.

Jean and I went to be with him for the last time. After two wildly stressful days, we were thankful he didn't have to die alone, and we were able to tell him we loved him and that it was okay to go.

Wayne's face immediately relaxed, and he moved his jaw around in grateful relief. His hands lightly squeezed ours ...

At 10:56 p.m., the CPAP mask was removed and all medications discontinued except for pain. Wayne's face immediately relaxed, and he moved his jaw around in grateful relief. His hands lightly squeezed ours, with Jean holding his right hand and me holding his left. He was no longer receiving any sedatives, so whether any of those movements were conscious remains a mystery, but we both felt he was saying goodbye.

Tears formed in the outside corners of his eyes, but they did not open. His heart stopped at 11:35, Dec. 15.

This only scratches the surface. With a few notable exceptions, dealing with the hospital staff during Wayne's last days was a nightmare, even for me as an experienced hospital and hospice chaplain.

An advance healthcare directive and medical POA would have made the entire experience much less stressful for everyone. What's more, Wayne died without a will, so settling his estate was another intense challenge.

Be sure all your end-of-life documents are current. The sooner you do so, the better. You may change your mind about details when faced with a life-threatening illness or injury, but having had the necessary family conversations will make things go much smoother.

Who ya gonna call?

– Unsung staff support our volunteer corps –

From Executive Director Mary Ewert

Springtime greetings! I hope you are enjoying longer days and a hint of spring in the air as much as I am. This seems a good time to introduce – or reintroduce – you to that small group of people who form FEN's paid staff and tell you a bit about what they do to help us fulfill our mission.

FEN has three full-time employees – Client Services Director Lowrey Brown, Executive Assistant Heike Sanford, and me. In addition, we have two part-time, paid consultants. Webmaster Melanie Raine wears several hats. In addition to updating website content, she manages e-blasts and provides administrative support to the FEN Speakers Bureau.

Lowrey Brown

Lily Chambers manages the Right to Die News Service and supports various board projects as well as volunteering as an Associate Guide.

In early March, Lowrey and our stalwart Training Committee organized a very successful Exit Guide Program training. This group of 20 trainees comes to FEN with amazing credentials.

Heike Sanford

The training was supported by a $25,000 grant from the SN Charitable Foundation, made in honor of Derek Humphry. A foundation representative who joined us for the training dinner was impressed by the background and experience of the trainees as well as the organization of the training program. FEN is fortunate to attract the support of donors who value our work, and we are grateful for that support.

Heike is our "boots on the ground" in Tallahassee, and the first point of contact for member services. She answers the mail, monitors online donations, updates the database, delivers incoming checks to our accountant's office, prepares thank you and renewal letters, mails welcome packets to our new members, and myriad other tasks.

Recently, Heike has received a number of requests for the U.S. Advance Care Plan Registry (USACP) application form, which is mailed to new members in their new-member packet. If you joined many years ago, you might not have saved the form.

If you are now considering the registry, go to the "Connect With Us" link at the very top of the FEN website, select "Membership, Donation, and Other Administrative Questions," and specify "Need USACP Registry form" in the Comments section. You will receive a cover letter, including instructions and Registry contact information, along with the form.

Lily Chambers

Note that we can provide the form but cannot help you complete it or upload your documents. The registry office is very responsive and can answer your questions.

Do you have a general membership question? Submit it by using the "Connect With Us" link at the very top of the FEN website, select "Membership, Donation, and Other Administrative Questions."

Melanie Raine

For questions about Exit Guide services, select "Exit Guide Service and End-of-Life Options."

We look forward to hearing from you.

In closing, the FEN staff recognize that we could not operate without the untold hours of time that our board and volunteers devote to our organization.

Volunteers are our lifeblood, and we aim to keep it that way!

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VISION

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

MISSION

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

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QUARTERLY MAGAZINE / BLOG

Jay Niver

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

Ohio MD acquitted after 14 fentanyl deaths

By Jay Niver, FEN Editor

An Ohio doctor accused of ordering excessive amounts of fentanyl that led to multiple patient deaths at a Columbus-area hospital was acquitted in April of 14 counts of murder after a lengthy trial.

Dr. William Husel, 46, was accused of ordering the powerful painkiller for patients in the Mount Carmel Health System. Prosecutors said prescribing large dosages for non-surgical situations indicated an intent to end lives.

Husel's attorneys argued he was providing comfort care for dying patients, not trying to kill them.

The verdict holds two messages for the right-to-die cause. First, even with what looked like a slam-dunk case against Husel, the jury let him walk. Second, the fact that he even faced murder charges should give impetus to states considering new right-to-die (RTD) legislation: It shows what a well-meaning physician can face with no Medical Aid in Dying law to protect them.

Husel would have faced life in prison with parole eligibility in 15 years had he been found guilty of just one count. The alleged victims were ages 37 to 82.

Prosecutors put on 53 witnesses. Medical experts said Husel ordered up to 20 times as much fentanyl as was needed to control pain. He gave enough to some patients to "kill an elephant," testified Dr. Wes Ely, a Vanderbilt University physician and professor.

Mount Carmel fired 23 nurses, pharmacists, and managers involved in administering the drugs, and reached settlements for more than $16.7 million over the deaths of 17 patients, with more suits pending.

[To be continued…join us in the next edition for our interview with Jose Baez, attorney for Dr. Husel.]

A dying grandpa's request to an 8-yr old began her lifelong, unafraid awareness of death

By Jay Niver, FEN Editor

PICK OUT MY LAST SUIT

FEN's new board member, Randee Laikind, had an early introduction to death and dying. It's one that taught her not to be fearful, because "it's a natural part of life."

It was her grandfather who schooled her when living with Randee's family in Philadelphia. He was dying of pancreatic cancer. She was 8 years old, she recalls, when he asked her to "Pick out the suit I should wear after I die."

They went to his closet, and she used her best child's judgment. Randee doesn't know if anyone ever saw him in it. Grandpa died in his sleep, likely wearing PJs, not his Sunday best. He was cremated, she remembers, and there might have been a service beforehand.

If he never wore her chosen threads, it doesn't matter to Randee. Point is, her first exposure to death came from a loving grandfather who wasn't frightened by the thought of moving on.

Afterward, his death continued her "schooling" in an indirect way. Randee says her mother "was devastated" by her dad's death, so daughter and granddaughter visited *him* every weekend in an old, Victorian Philly building. His ashes were interred there in a columbarium that was a logical extension of the on-site crematorium.

"I played there every week, where people were being cremated, and their urns were placed in the little compartments with a glass window," she says. "I took my sketch book and drew pictures."

Randee went on to earn a degree in fine arts (painting), and that merged with a lifelong passion for making art from fiber.

"I was the granddaughter of two tailors from Ukraine, so I have the textile gene," she explains. When interviewed for this story, she was weaving bath towels for her son (something you won't find at Bed, Bath & Beyond).

When you mention "dying" to Randee, she thinks first about *dyeing* cloth, not meeting your maker. Knitting, spinning, sewing – she is the maker of almost anything fiber.

"I have way too many fleeces. It's a bad addiction," she confesses. And, while she never fleeces anyone on two legs, she works closely with four-legged sheep and helps others raise them.

"I have a thing for sheep, and I have friends who have them. I don't own any, but I'm very involved," she explains.

She was once involved in shoes, as well.

"I went to buy some for my son, and I didn't want to put him in brown shoes. That's so boring!" So, she opened her own shoe store (*Stepping Up*) "and kids could have colorful shoes."

Randee joined FEN in 2004, but her EOL involvement in western Massachusetts began long before. She worked intimately with hospice starting in 1976 and was president of the regional Hemlock Society in 1984; in 1985, she joined the board of Funeral Consumers Alliance.

Her major career contribution was 22 years directing court-appointed special advocates (CASA) for Friends of Children in Hadley, Mass. She managed volunteer services, fundraising, and case management among other duties. Earlier, she spent five years working nearby in elder services.

As for joining FEN's board of directors, Randee said President Brian Ruder "has been recruiting me from day one. I finally gave in."

Creativity looms when new FEN board member Randee Laikind weaves her magic as a textile artist.

Elder law attorneys – 1st & last line of defense

By Janis Landis, FEN Board Member

Many people use an elder law (or estate law) attorney to "settle" their legal affairs. They prepare a will and perhaps a power of attorney for financial affairs. Depending on their circumstances, they may prepare appropriate trusts and other financial documents.

Then, as kind of an afterthought, the client also hands the attorney their Advance Directive for Health Care and their Designation of Health Care Surrogate (or similar documents.)

Most people do not realize that their lawyer's most important work on their behalf may be down the road. Your attorney can be your best advocate for ensuring your healthcare wishes are enforced.

Under the federal Patient Self Determination Act of 1990, you have a right to refuse medical treatment for yourself, and your surrogate can do so on your behalf. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides additional rights, such as obtaining a copy of your medical file.

But all too often, those rights are not honored. Here are some real life examples:

● A nursing home ignores the patient/surrogate directive for palliative care only, and sends the patient to the hospital;

● A hospice denies a patient adequate pain relief;

● A doctor refuses to discharge a patient unless the patient agrees to continue treatment such as an IV line (often called a PICC);

● A nurse reports the surrogate to Adult Protective Services for not insisting on aggressive treatment;

● Medical staff does not recognize the authority of the designated surrogate;

● A medical office fails to transfer health records to a new doctor despite repeated requests.

Although you or your surrogate may be very articulate and forceful, this may not be enough.

Your elder law attorney is the ideal professional to ensure your rights are respected. In the preceding cases, a phone call or letter from the lawyer can often bring immediate compliance.

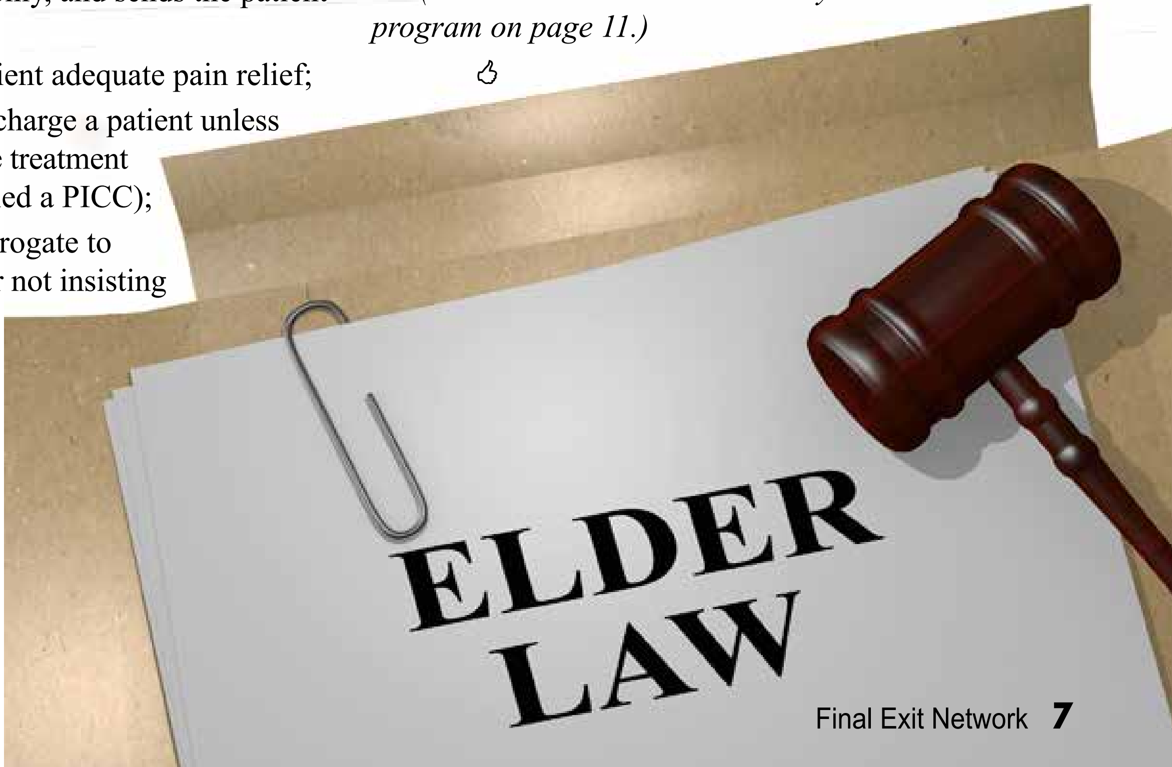
Sometimes, despite best efforts of the patient and their surrogate, things go terribly awry: The hospital ignores the Advance Directive and provides aggressive, invasive treatment, resulting in months of needless suffering.

These egregious cases have prompted a new type of medical lawsuit: a "wrongful prolongation of life." Already, cases in Georgia, Alaska, and elsewhere have resulted in large monetary settlements and, more importantly, have put hospital administrations on notice that there are severe consequences for failure to adhere to an Advance Directive.

Pending cases in New Jersey and New York have been given the green light by courts to proceed.

In cases like these, your attorney's intervention can be the critical last line of defense. Remember, when you hand your signed forms to your attorney, you're handing them not just a piece of paper – but also the key to ensuring your peaceful, dignified death.

(Editor's note: See related story about a new FEN program on page 11.)



• Residency mandates could fall / M

OR decision, CA suit may c

By Jay Niver, FEN Editor

Since Oregon passed its landmark right-to-die (RTD) law in 1997, so-called "death with dignity" legislation has gained a steadily growing foothold across the United States. Today, one-in-five Americans (theoretically) has access to Medical Aid in Dying (MAiD), in 10 states plus the District of Columbia.

In every jurisdiction where MAiD is legal, the laws have essentially followed the Oregon template, including standard provisions to prevent abuse. Two of those foundational pillars are now being shaken – even threatened with collapse.

Through legal challenges, plaintiffs have:

- Won an Oregon decision that could impact RTD laws everywhere, and influence states that have none;
- Brought suit in California to eliminate the requirement that all MAiD patients must self-administer their life-ending drugs.

Oregon agreed to a settlement in late March with a resident physician in a federal lawsuit alleging that the state's residency requirement violates the U.S. Constitution's guarantee of equal treatment.

> ***'The unambiguous implication is that other jurisdictions with MAiD will sooner or later be forced to strike their residency requirements.'***

The agreement requires Oregon officials to issue directives halting enforcement of the law's residency provision, and initiate a legislative request to permanently remove residency language from the law.

"The Oregon decision is a national game changer," said Edmund Tiryakian, a lawyer and executive director of Dying Right North Carolina (DRNC). "For the first time, everyone in the U.S. – including all the states that don't recognize MAiD – now has legal access to the procedure in Oregon. They need only make their way there, contact a doctor willing to write a prescription, comply with the other requirements of the (MAiD) law, and decide the time and place within Oregon to self-administer.

"There is no longer a requirement to go through the lengthy and tiresome process of first establishing legal residence."

The suit was brought by Dr. Nicholas Gideonse, who is licensed in Oregon but not in Washington state. He practices in an area bordering an underserved part of Washington, and some patients from there come to him for end-of-life care.

Suffering people who deserve aid in dyin
for help – and if they're incapable of takin
seeks to permit a physician to assist on t

Compassion & Choices provided his legal team and joined in the lawsuit.

Their argument was basically this: If Americans are free to receive healthcare across state lines for any other procedure (which they routinely do), how can they be denied a chance to access Medical Aid in Dying?

Tiryakian raised another point about the Oregon precedent: Will other MAiD jurisdictions follow suit?

He explained: "The Gideonse decision was made before a federal judge – the case was settled before the judge could decide on the merits. But it was clear to the state defendants that the residency requirement was manifestly unconstitutional.

"The Privileges and Immunities Clause of the 14th Amendment prohibits a state from denying vital medical services to an out-of-state citizen in preference to an in-state resident."

Tiryakian continued: "The unambiguous implication is that other jurisdictions with MAiD will sooner or later be forced to strike their residency requirements. This means aid in dying will be accessible to citizens throughout the country – there are MAiD states on both coasts, and in Colorado and New Mexico, not to mention the possibility of an end-of-life vacation in Hawaii."

The Oregon decision could also impact states that are considering RTD legislation. Said Tiryakian, "If

MDs might administer medication •

change US RTD landscape

g may have the right to travel out of state
ng prescribed drugs themselves, a lawsuit
heir behalf.

someone can drive a reasonable distance for a peaceful death in another state, shouldn't non-MAiD states reconsider? If their residents can simply leave the state, shouldn't compassionate lawmakers make it easier for their own constituents to stay home for the help they deserve?"

The goal of DRNC, Tiryakian's advocacy group, is to legalize Medical Aid in Dying in North Carolina. He has gotten bills filed in the past four legislative sessions, but none has advanced to a committee hearing.

"We get calls from desperate, dying people who ask us, 'What can I do?'" he said. "I used to tell them, 'Go to Switzerland or try VSED (voluntarily stopping eating and drinking).' Now they have a third option: Go to Oregon."

California case may be more impactful

As significant as the Oregon decision may be, a lawsuit in California may ultimately have an even bigger impact on the right to die in America.

The state's End of Life Option Act (EOLOA), signed into law in 2016, is being challenged as discriminating against people with disabilities. The statute, like every other American MAiD law, requires patients to self-administer their life-ending medication. No physician or other person may assist: Taking an active role would constitute euthanasia, which is illegal in the U.S., though permitted in Canada and six other countries.

Plaintiffs in the suit want to include a provision in the EOLOA that allows a doctor to help physically disabled people ensure their end-of-life prescription drug can be properly taken.

In an April hearing, attorney Cat Cabalo told U.S. District Judge Vince Chhabria that some patients are so physically incapacitated by their disease, infirmity, or old age that they can begin the assisted-dying process but lack the strength to finish it.

She said not allowing a doctor's assistance is a violation of the Americans With Disabilities Act (ADA) because it discriminates against some physically disabled persons. They may be unable to grasp, swallow, or otherwise function to realize their life-ending wish.

In short, California's EOLOA does not give them access to a legally sanctioned activity (MAiD) that is available to other, able-bodied people.

Matthew Renda covers the San Jose Federal Courthouse and reported after the hearing, "Chhabria appeared more favorably disposed toward Cabalo than the arguments of the attorneys representing the state of California."

Renda quoted the judge asking Cabalo, "So, once the state decides to give people the ability to commit suicide, the state is required to go a little bit farther to accommodate the disabled, who have the right to have their doctor give it to them?"

Renda said Cabalo agreed – that was an accurate characterization of her argument.

Renda was optimistic that the judge was considering plaintiffs' case: "It appeared, given the line of questioning that Chhabria pursued ... that he became more and more persuaded that Cabalo did indeed have a point about where the ADA laws intersected with California's assisted-suicide law."

Renda added, "It was clear that old-fashioned lawyering may have moved the needle on (this) weighty question."

The court's ruling may be known by the time this magazine is delivered.

Regardless of Judge Chhabria's decision, the debate over physician assistance – coupled with what may be a move to drop states' residency requirements – means the face of American MAiD could soon be dramatically changed forever.

Death would not be called bad, O people, if one knew how to truly die. – Nanak

A tale of 3 deaths

Mourners remember a woman who died a bad death unnecessarily in April.

By Althea Halchuck,
FEN Surrogate Consultant

Nancy Cruzan was in a 1983 car accident that left her on life support for the next eight years. Her parents petitioned the U.S. Supreme Court to remove her feeding tube but were denied. However, in a landmark decision, the court ruled that under the U.S. Constitution, competent adults had the right to refuse medical care. In December 1990, her family could finally remove her life support. Nancy experienced a bad death by any measure.

In her *Washington Post* op-ed, *The Long Death of Nancy Cruzan*, Ellen Goodman claimed: "Her death did not come gently to any of the Cruzans. Nancy came to represent the unintended consequences of technology, the side effects of our best intentions, and the cruelty of our modern medical mercy. She came to represent something worse than death."

Thirty years later, people are still confused about their medical rights. Recently, a friend's patient said she wished she didn't "have to have" another round of chemo. The woman said she just wanted to be able to enjoy this one last summer – but with chemo, she would be sick all the time, ruining everyone's summer.

My friend asked why she thought she "had to have it," and the woman said her oncologist would be "upset if I didn't." She knew the cancer was killing her, and more chemo would not do her any good. However, her family insisted she needed to "keep fighting."

I can imagine what her summer might be like without chemo. She would be free to enjoy it with a bittersweet poignancy, knowing it's her last. She could take walks by the seashore, feel the sun, breathe the salty air, and listen to the song of the waves.

Rather than spending her summer dealing with the side effects of poisons, she might spend quality time in the days she has left. She could have heart-to-heart conversations while gently preparing her loved ones for her eventual departure, so no one has any regrets or leaves anything left unsaid.

Opting for the promise of summer rather than the rigors of chemo, she may create many happy memories that her family and friends will cherish long after she is gone. She would make the most of her remaining time by letting nature take its course.

The choice is a trade-off: less quantity of time, but often, more quality. *Most would describe that as a good death.*

This week I learned of a different, bad death (like Nancy's). In late January, a friend was diagnosed with stage-4 cancer in her lungs, which metastasized to her liver and bones. At first, some medico said she was "terminal" and suggested "comfort care." But instead of meeting with a hospice team, oncology took the lead. Her oncologist "talked her into" the latest immunotherapy treatment, not a cure, but something to make him feel like they were doing something.

Once she started the treatment in mid-February, he assured her and the family she'd feel better, and her appetite would return, "maybe in 6-8 weeks." Instead, the quasi-treatment only added to her suffering and delayed her going into hospice.

... she told her girls she 'didn't want to disappoint her oncologist by giving up.'

Her two daughters told me individually that they thought she should have been using hospice from the start. Instead of making the most of the time she had left, which is the promise of hospice, she told her girls she "didn't want to disappoint her oncologist by giving up."

From diagnosis to death, it was two months. During those weeks, she was on infusions for a useless Hail Mary treatment, all of which robbed her and the family of precious time to talk about what mattered most. Her final wishes were to go to the beach and to hug her grandkids, but the choice to have infusions robbed her of those simple pleasures.

She went into the hospital again for a severe breathing problem brought on by yet another pneumonia. The ER attending said the tumors "were taking over her lungs," and her "death was imminent." He could see how she was struggling and suffering.

She went on hospice that afternoon. Her daughters told me they wished the oncologist had told their mom the truth and not "lied about some miracle therapy."

My friend died in the hospital two days after going on hospice, with her family around her – *but everyone had a bad death.*

Dr. Atul Gawande, in his seminal work, Being Mortal, talks to the widower of his cancer patient, Sarah, a new mother who died from lung cancer. Dr. Gawande told the husband he regretted telling them a scheduled experimental lung cancer treatment might also cure her thyroid cancer. He says he regrets it "because I knew it was a complete lie. I just wanted to have something positive to say."

Sarah spent her final week enduring brain radiation. Her husband regrets "chasing one useless therapy after another," hoping for that elusive cure but, in doing so, sacrificing any quality time they might have had as a family.

New FEN program helps prep attorneys

FEN has developed a program for attorneys who specialize in practicing elder law, to ensure they are fully aware of their responsibilities and rights in representing their elderly clients.

This first-of-its-kind training has been certified by the National Academy of Elder Law Attorneys (NAELA) for credit toward Continuing Legal Education.

"Our first presentation was given in April to the Illinois chapter," said FEN Board Member Janis Landis. "The response was extremely enthusiastic, and, as several participants commented, it was 'eye-opening' on the issues clients face and the importance of the lawyers' on-going responsibility to them."

The impetus for the training module came from an Illinois lawyer's inquiry, wanting to learn about FEN. Landis said it became evident that the attorneys were eager to know more about end-of-life issues and challenges, so she put together the Zoom program.

"So often, elder-law attorneys are never contacted until *after* someone dies," she said. "It seems like 90 percent of what they do deals with estates and financial matters. All the advance planning that relates to other things – they rarely get to it ... Everything around healthcare is vital, but so often it gets overlooked."

Few people want to deal with their own death and dying, said Landis, so their lawyers can't help until it's too late. They are never asked for help. "That's why it is incumbant upon elder-law specialists to be aware of what needs to be done," she added.

FEN will be contacting NAELA chapters around the country, armed with the success of the first presentation and an endorsement from the Illinois group.

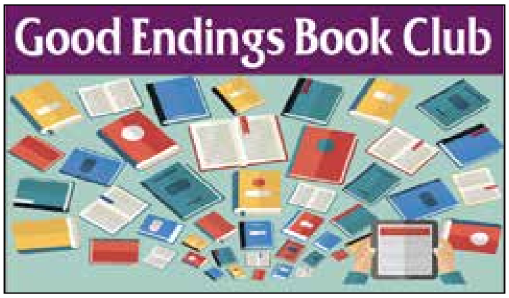
If your lawyer isn't familiar with healthcare issues, tell them about the FEN program. It's free and can be certified for legal education credits.

(Editor's note: See related story on elder-law attorneys on page 7.)

Much heralded new book earns mixed review

Ignoring FEN perpetrates ‘Swiss Myth’

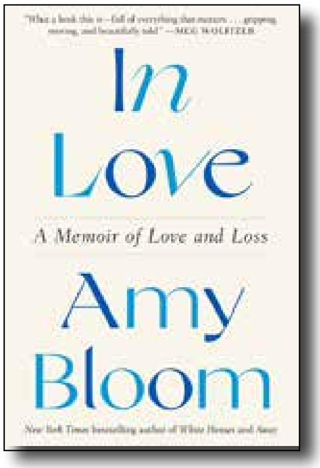
By Jim Van Buskirk,
FEN Member / Chief Reviewer



... it is a myth that only Switzerland holds a dignified end-of-life option for ill, suffering Americans ...

In her new book, In Love, A Memoir of Love and Loss, the renowned novelist (and psychotherapist) Amy Bloom offers a closely observed chronicle of her experience traveling to Switzerland with her husband, Brian Ameche. Diagnosed with early-onset Alzheimer’s, he made the decision to hasten his death in 2020.

Although this well-written memoir is receiving a lot of media attention, I’m not quite sure whom Bloom intended the audience to be.



She justifies the necessity of the trip throughout the memoir. “Dignitas is a Swiss nonprofit organization offering accompanied suicide ... the only place to go if you are an American citizen who wants to die and if you are not certifiably terminally ill with no more than six months to live,” Bloom writes.

This is the current U.S. standard in the 10 states plus the District of Columbia where Medical Aid in Dying (MAiD) is legal. Bloom says “... many older or chronically ill Americans harbor end-of-life fantasies” about these jurisdictions, and she researched them “at Brian’s direction.”

“We discovered that the only place in the world for painless, peaceful, and legal suicide is Dignitas, in the suburbs of Zurich.” Later, she adds, “... it became clear that Dignitas was Brian’s best choice and probably, really, his only one.”

As FEN members know, these statements are false. FEN requires no terminal illness for those accepted to receive Exit Guide services. A “constellation” of medical and personal circumstances may be enough, and applicants must pass screening by FEN’s Medical Evaluation Committee.

What is not apparent is if Bloom and Ameche were unaware of Final Exit Network, or perhaps FEN could not meet their specific needs around his dementia.

Regardless, it is a myth that only Switzerland holds a dignified end-of-life option for ill, suffering Americans, even where MAiD has been legalized.

Later, Bloom claims, “I do a close read of Exit International’s website,” but she apparently doesn’t investigate their informative publication, The Peaceful Pill Handbook.

At one point, Bloom poignantly addresses their friend Rachel’s having missed her window of opportunity, and she ended up living for years with Alzheimer’s.

“Choosing to die and being able to act independently while terminally ill is a deliberately narrow opening. Many people can’t get through it,” she writes. “They either can’t swallow well enough. They can’t talk well enough. They can’t hold the glass or mix the drink on their own ... People who do wish to end their lives and shorten their period of great suffering and loss – those people are out of luck in the United States of America.”

This passage is misleading without context.

It’s true that all MAiD patients must be able to self-administer their drugs, and they must be mentally competent to receive a prescription. No MAiD law is available to someone with dementia.

But surely not every American with “suffering and loss” is “out of luck” without a trip to Switzerland.

Her statement, “We pin our hopes on Dignitas because the right-to-die laws in America are not going

Amy Bloom

to help us" is all too true – assuming "us" refers to people with dementia.

Perhaps in an effort to establish intimacy with readers, Bloom offers detailed descriptions of what clothes they're wearing, how much things cost, what meals they eat at which restaurants, and other over-sharing – seemingly without regard for their relative position of privilege. Though she accepts a generous gift from her sister to cover the expenses, she seems unaware that a trip to Europe is beyond the means of many Americans.

Bloom is best when describing Dignitas's rigorous application process and the frustrations of obtaining required records from her husband's psychiatrist, neurologist, internist, and other practitioners. These details speak well to the fact that the medical industry is not helpful or supportive to many people who must rely on them, not to mention the sadness and frustration experienced by those who feel they cannot be honest about their own attitudes surrounding death.

Bloom leavens this depressing situation with appropriately dark humor: "As my sister said, 'It's like you do everything you possibly can to get your kid into Harvard and when you do, they kill him.' Ellen was horrified it came out of her mouth and I was horrified to hear it, but she wasn't wrong."

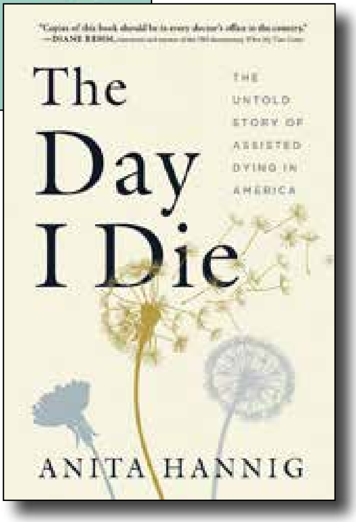
Ultimately, Bloom's book doesn't offer much hope to people seeking a road map to find help at the end of life, particularly when dementia is involved. And with our aging population and increasing rates of dementia, it is a huge issue in our country (with almost no one offering any kind of understanding or support).

Referring to legal issues surrounding Lifecircle, a Swiss clinic similar to Dignitas, Bloom claims "... you can't find it anymore ..." Actually, a lawsuit is behind them, and Lifecircle is accepting clients. For a subject like this, both author and publisher must do their best to make sure their information is as up-to-date as possible.

Although well-intentioned, Bloom's memoir feels a bit off target. Its out-of-chronological structure, repetitions, and self-deprecations unfortunately undermine its importance as a poignant and powerful portrait of an intensely personal journey.

More Good Endings

The Day I Die



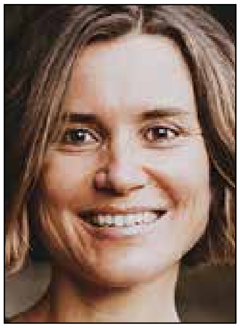
By Anita Hannig

Reviewed by Jim Van Buskirk,
FEN Member / Chief Reviewer

"Everybody in Oregon knows that we have this law. But nobody has a clue how it works."

Quoting an end-of-life volunteer, Anita Hannig carefully and concisely pulls back the curtain on the intricacies of the complicated and controversial process of assisted dying. She focuses on Oregon, reminding readers that the other jurisdictions that have Medical Aid in Dying (now 10) have used that state as a model for their versions of a RTD law.

Hannig, an associate professor of anthropology at Brandeis University, immediately inserts herself into the story she's telling, making her lucid prose that much more personal as she accompanies volunteers into various situations, allowing for a detailed perspective on quotidian aspects of the sometimes stigmatized topic.



Anita Hannig

Hannig clearly disambiguates suicide, assisted dying, and euthanasia, and also palliative care and in-home versus special-facility hospice. She quotes patients, medical professionals, religious figures, family members, and legal experts about their firmly held and/or sometimes shifting moral, legal, or medical beliefs, either advocating for or opposing our right to die.

She emphasizes that "the widespread moral ambivalence and religious opposition toward assisted dying have majorly complicated its implementation."

She respectfully addresses the challenges presented by depression and mental illness, the problematic aspects of requiring a six-month prognosis, and the dubious "slippery slope" arguments, as well as those voiced by disability-rights spokespeople.

> ***... just having a conversation with a doctor about assisted dying sometimes puts a patient's mind at ease ...***

As a result of her deep involvement, Hannig, while fairly representing opponents' perspectives, reveals herself as a committed proponent of the medical modality.

Observing that "most people who are caught in the turmoil of terminal illness have little bandwidth to take on the logistical and emotional costs of figuring out how to qualify for assisted dying," she acknowledges that "not all families are prepared or comfortable to offer this type of support."

Citing one physician whose "professional integrity rose above the patient's autonomy," she maintains that "just having a conversation with a doctor about assisted dying sometimes puts a patient's mind at ease, and they never initiate the process."

Out of 6,200 physicians in Oregon, 142 prescribed medications under the Death with Dignity Act in 2020.

Other useful information included in this timely snapshot of the topic are a reading group guide, an interview with the author, and a short list of relevant resources. Because it is not pertinent to her focus on MAiD, there is no mention of VSED, Final Exit Network, Swiss clinics, the book Final Exit, The Peaceful Pill Handbook, or any other options.

Hannig notes a silver lining in assisted death: "Knowing when their loved one will die has allowed families to be more intentional about beginning the task of mourning – including forgiveness, honoring, and farewell – before the time of death, sometimes supported by ceremony and ritual."

The Day I Die is an important addition to the growing canon of recent books on this subject, like Stefanie Green's This is Assisted Dying (focused on Canada); Mara Buchbinder's Scripting Death: Stories of Assisted Dying in America; and Katie Engelhart's The Inevitable: Dispatches on the Right to Die.

THE BACK PAGE

A COMPENDIUM OF RIGHT-TO-DIE WORLD NEWS

United States

• **Texas** – The 3-year-old toddler at the center of a years-long fight to keep her alive was released home from the hospital in April.

Tinslee Lewis was born prematurely in February 2019 with Ebstein anomaly, a rare and often terminal heart disease that requires significant intensive care. On October 31, 2019, Cook Children's Medical Center in Fort Worth invoked the "10-day rule," a state law that allows a hospital to tell a family that they will remove treatment at the end of a 10-day period.

Tinslee's family fought the measure and won a restraining order; then a local trial court ruled in the hospital's favor. The Fort Worth Second Court of Appeals granted the family an emergency motion and eventually said Cook Children's decision to remove treatment violated the mother's due-process rights.

In January 2021, the case found its way to the U.S. Supreme Court on appeal by the hospital, which continued to seek to remove treatment from the toddler. The court declined to grant the appeal.

• **Maine** – Oregon's recent decision to drop its residency mandate (see pages 8-9) for MAiD patients is sparking conversations in other states.

MAiD critics claim Oregon will become a magnet for "suicide tourism," as would Maine if its residency requirement is invalidated.

Valerie Lovelace, executive director for Maine Death with Dignity, disagrees. "I want to emphasize, that's not going to open floodgates for people who will suddenly be rushing to (other states), because the process doesn't work like that," she said.

Lovelace said that Oregon deciding to offer MAiD to non-residents may set a precedent. "I think the other states that have (MAiD) laws are going to have to be looking at and considering, is this something we ought to do too?"

Great Britain

Severely ill and dying Brits are more than twice as likely than the general population to end their own life, official data have revealed.

First-of-its-kind analysis found that 978 patients in England with one of three severe, often terminal health conditions died by suicide between January 2017 and March 2020.

Right-to-die campaigners warned that the data show large numbers of desperate Brits are "taking matters into their own hands" in the absence of legal routes to an assisted death.

The research found suicide rates for patients with low-survival cancers (a year after diagnosis) were 2.4 times higher, the same rate as those with COPD. Patients with chronic ischemic heart conditions were nearly twice as likely to die by suicide.

The data follow a series of high-profile suicides by terminally ill people, including Formula One boss Max Mosley and Dr. Christopher Woollard, a professor with cancer who stole and crashed a plane to end his life.

It also comes as the Crown Prosecution Service considers an update to its guidance on prosecuting mercy killings and suicide pacts in cases where the deceased was seriously ill with a settled wish to die.

Canada

A Canadian church was the site of a recent assisted death in a ceremony that was held for one of its elderly members. A "Crossing Over Ceremony" was held at Churchill Park United Church of Winnipeg for Betty Sanguin, 86, who had been diagnosed with ALS.

It was the first instance in Manitoba where MAiD took place in a church. The entire procedure took 15 minutes, and Sanguin died with loved ones beside her.

"It was perfectly natural to hold this service for Betty in our sanctuary because death is a natural part of life, and Betty had lived a good part of her adulthood in this faith community," said Pastor Dawn Rolke.

* * *

FINAL EXIT NETWORK
PO BOX 10071
TALLAHASSEE, FL 32302

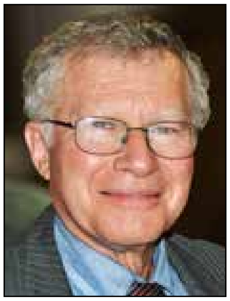
MAiD CRITICS CLAIM:

RIGHT TO DIE LEADS TO DUTY TO DIE

Addressed by David C. Leven
Executive Director / Senior Consultant, End of Life Choices New York

This is an absurd argument, that people will feel a *duty* to end their life.

At least since 1990, patients have had the right to die by stopping or never starting treatment that is, or might be, life-sustaining. Any adult patient with decision-making capacity can reject life sustaining treatment although death will result, whether by refusing to accept treatment when first offered, or by having the treatment discontinued.


David Leven

This right even extends to those who are not terminally ill. However, very few patients reject life-sustaining treatment, unless they are close to death.

There is no evidence that those who have Life-Sustaining Treatment (LST) withdrawn feel that they have a “duty to die.” So, understandably, in the context of LST, the argument has not been made that those patients will feel a “duty to die.”

Life is precious. And so, despite having the right to die, the vast majority of patients choose to live, at least until suffering becomes (or is becoming) unbearable, usually when death draws near. There is simply no evidence, over almost three decades, that patients are in any way feeling obligated to die.

People who ultimately choose Medical Aid in Dying (MAiD) would prefer to live, but are now dying. They only want to control the manner and timing of their deaths, just as do patients who hasten their deaths by withholding or withdrawing life-sustaining treatments or who die by voluntarily stopping eating and drinking (VSED).

There is now cumulative evidence totalling 60 years on the experience of MAiD in America. Patients who choose this option are clearly not rushing to end their lives because of a perceived duty to do so.

To the contrary, the facts conclusively show that very few people die by MAiD – only about three of every 1,000 U.S. deaths. And, even among those patients who obtain the medication, about a third never take it, further evidence that patients are not feeling an obligation to end their lives.

And, the MAID process usually takes about seven weeks from the time that a prescription is first requested until the medications are taken, indicating that patients are acting in a thoughtful manner, almost always with the support of their families.

Fear mongering about a potential “duty to die” has no basis. And, one wonders if some MAiD opponents may think there is a duty to live, even when suffering is intolerable at the end of life.