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Speaking Out

People with disabilities deserve access to aid in dying

Debunking the claim that MAiD puts anyone at risk



Rachelle Chapman

By Jay Niver, FEN Editor

The battle for Medical Aid in Dying (MAiD) is difficult. But for people with disabilities, the challenge is even more daunting.

Some groups who claim to fight for disability rights work vehemently trying to deny the right to die (RTD), not only to the disabled community they supposedly

represent, but also to everyone else.

“I should have access to any law that anyone else has access to, and that includes the right to die,” says [Rachelle Chapman](#). “Anyone with a disability who has a problem with the right to die – for all people – makes no sense to me. There are a lot of things that people

SPEAKING OUT *continued on page 2*

Despite widespread agreement that those with disabilities deserve equal treatment, the ‘rights’ groups that purport to represent them would deny their access to a basic human right: the right to a peaceful, dignified death of their choosing.

SPEAKING OUT continued from page 1

don't have access to. We are discriminated against, and I'm all about fighting those things – but the right to die is not one of those issues.”

Chapman knows about disabilities. Her best friend gave her a playful push into a pool at Rachelle's bachelorette party in 2010. She immediately knew she was paralyzed. After 14 months of medical procedures and rehab, her marriage took place using a wheelchair.

She remains quadriplegic with little use of her hands, but she has earned a compelling media presence with her story of perseverance and survival.

In spring of 2015, she and husband Chris welcomed daughter Kaylee, who was born via a surrogate. Later that year, Chapman's revealing lingerie shoot made an edgy but powerful statement that people with disabilities can be sexy. (No effort was made to conceal her catheter and ostomy pouch.) Chris and Rachelle renewed their vows in 2020, which garnered additional news coverage.

‘The Resistance’

Chapman knows there are some advocacy groups “who believe that this is some huge conspiracy to get rid of people with disabilities, like it's targeting them,” she says. “In fact, this is not denying rights, it's *expanding* rights.”

Despite widespread agreement that those with disabilities deserve equal treatment, the “rights” groups that purport to represent them would deny them access to a basic human right: the right to a peaceful, dignified death of their choosing.

Not Dead Yet (NDY) is the most high-profile national group to assail Medical Aid in Dying. In fact, that is all they do. (See their statement above.) They exist solely to oppose MAiD for anyone, whether or not they have disabilities.

[Dr. “BJ” Miller](#) doesn't think any group can claim to speak for all people with disabilities. Miller, a TED talk star and renowned advocate for healthcare reform,

lost parts of three limbs in a college accident.

“The ranks of the disabled in this country are an extremely diverse population. There are people of every political stripe, and the degrees of abilities and disabilities are profound,” says BJ. “The idea that ... one organization could speak for all people with disabilities I think is just naïve.”

In January, Chapman recorded her right-to-die views in a video shot in her Knightdale, N.C. home. It will be shared online, and wherever anyone welcomes a logical, reasoned response to MAiD critics' arguments.

Chapman says NDY does not speak for her: “As someone who has a disability, I personally have the ability to think for myself, and nobody's going to prey upon me, convincing me that I should end my life.

That's just not how it works.”

Real Issues

America has a long, shameful record of mistreating marginalized people, including those with disabilities. Says Miller, “There is a dastardly history in this country, and in the West, around the treatment of people with disabilities. I don't think that the average American citizen really has a clue about the issues that face a disabled person.”

Like Miller, Chapman knows of real hurdles. She



BJ Miller, MD

says she “would have a lot to say” to Not Dead Yet: “You are fighting the wrong fight. There are so many other issues out there that include affordable housing and affordable healthcare – those are worthy causes, and I will stand with you on that. But when it comes

to dignity in dying, it is not a disability-rights issue.”

A Level, Non-Skid Surface

MAiD opponents – whether it’s NDY, the Catholic Church, or various right-to-life groups – rely largely upon baseless “slippery slope” arguments.

Since Oregon’s ground-breaking 1997 Death With Dignity Act, 60 combined years of U.S. MAiD have produced no evidence – not one documented case – of the law being used to abuse anyone, disabled or not.

Numerous safeguards are built into all U.S. RTD laws. Still, naysayers claim vulnerable patients will be pressured into taking their own lives, by selfish family members, “the healthcare system,” or simply because they feel devalued and don’t want to be a burden.

“I don’t believe the term ‘slippery slope’ should be an argument for any of this,” Chapman says. “I don’t think that’s right. I think what we should be doing is fighting for what’s on the table right now, and right now we’re talking about people who are six months’ terminal, whether you have a disability or not.”

Miller knows why some people envision the worst.

In some other countries, like Canada, a doctor can administer the drugs – and virtually everyone chooses assistance ...

“We send signals to each other that are pretty rough, including as a disabled person where you just feel like people are kind of suggesting that you should get off the planet,” he says. “But I don’t think that’s the fault of a Medical Aid in Dying law ... I don’t blame the law for causing or furthering that discrimination.”

The slippery verbiage of MAiD opponents can be found around the world, everywhere people seek a compassionate end to suffering from intractable pain or terminal illness.

This, from a New York State op-ed (*Times Union*):

If assisted suicide is legal, some peoples’ lives will be lost due to mistakes, coercion, and abuse ... this (law) would ... pose mortal danger to vulnerable and marginalized people.

Here’s what’s being said in Ireland, where assisted-dying is being seriously debated for the first time:

Assisted suicide enables the violation of the right to life of some of the most susceptible human beings ... it will place the weakest citizens at risk ...

RTD advocates – and some lawmakers who helped craft MAiD laws – now recognize that layers of safeguards to prevent abuse actually make it



Rachelle Chapman shares her story with Katie Couric.

impractical for many qualified patients to access that end-of-life option.

In some states, there have been efforts to liberalize existing laws. RTD supporters view this as progress – not a “slippery slope” that may lead to abuse.

Advocates also eye more-significant MAiD revisions – expanding eligibility to a pair of vast and growing groups: people with dementia, and those who are unable to self-administer the prescribed drugs.

Every Medical Aid in Dying statute requires the patient to take their lethal medication without help, and all who request a prescription must be of sound mind.

Those with severe Parkinson’s or ALS – maybe unable to swallow or use their hands – are excluded from having a compassionate end-of-life option.

In some other countries, like Canada, a doctor can administer the drugs – and virtually everyone chooses assistance, even if they are able-bodied.

The U.S. requirement to self-administer clearly discriminates against some people with disabilities, according to pro-MAiD attorneys, physicians, and patients who have filed suit in California against that state’s End of Life Option Act.

Dr. Miller agrees in principle: “Just because I can’t lift the tablets to my mouth to swallow the pills, that can’t be in the spirit of the law ... the law could be refined, could be more inclusive.”



Must I be a warrior?

– ‘Brave battles’ can’t fight fatal disease –

FROM EXECUTIVE DIRECTOR MARY EWERT



Be tough, be strong, meet challenges, fight the disease – the use of “warrior language” abounds among nonprofit disease organizations, and that language has always offended me both as a caretaker and as a person who might someday experience a fatal disease.

I’ve wondered if I’m just too sensitive to war metaphors. But I’ve found others who have a similar reaction. A bit of research shows that we are not alone.

The American Cancer Society “attacks cancer from every angle” and urges us to “fight together.” The Alzheimer’s Association asks us to “help fight Alzheimer’s.” The ALS Association encourages volunteers to “walk to defeat ALS,” to “help us in our fight against ALS.”

None of these organizations offers the information that many people with those diseases seek – how they might have a peaceful exit in the face of a fatal diagnosis.

In 2014, Kate Granger penned an article for *The Guardian* asking, “Why is military language used to describe cancer?” Granger, a National Health Service doctor and terminal cancer patient, observed: “‘She lost her brave fight.’ If anyone mutters those words after my death, wherever I am, I will curse them.”

While she understands that military language might be meant to encourage positivity at a difficult time in life, it can also have the opposite effect. Disease is part of a person’s body, not outside it. The person is living in a body that happens to be experiencing disease.

Terminal disease cannot be beaten.

Does that make the person a failure, someone who fought and lost? Is the person weak? How can this be when the person does not have the power to control the disease?

Researchers at the University of Southern California tested the “war on cancer” metaphor on a group of healthy individuals. They found that

Combative language actually had a negative effect, causing healthy people to avoid cancer screening because they perceived cancer as difficult to treat and impossible to control.

combative language actually had a negative effect, causing healthy people to avoid cancer screening because they perceived cancer as difficult to treat and

impossible to control.

Two disease organizations that took a softer approach encouraged people to live with hope and optimism, to support research “to unlock the mysteries” of the disease, to organize events “that fuel solutions” and “drive change to achieve real world results.”

While I find this quietly encouraging language much more effective than the language of battle, an important element is missing: How can a person with a terminal disease who is looking for all options find their choices?

Sadly, there is little discussion of the “end game” to be found.

Many callers who speak with Final Exit Network coordinators are hungry for that conversation, one that FEN offers them.

We are dedicated to filling that role and committed to expanding our outreach to the wider community, offering practical solutions and a sense of peace to those who seek truthful information.

They may not act on this information, but knowledge can give them a sense of peace.





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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

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.

VT eyes revisions to its RTD law

Vermont lawmakers are considering changes to the state's right-to-die (RTD) law that will make it less burdensome.

As in other states, built-in safeguards to deter abuse often end up preventing dying people from getting access to the end-of-life option designed to help them.

The drive to liberalize requirements was led by a former Vermont legislator who championed the original legislation almost 10 years ago, Willem Jewett. He died Jan. 12 using a prescription obtained through the law, beating terminal cancer to the punch. He was 58.

Before his death, he said he found the law's restrictions on patients and providers – including waiting periods, multiple in-person requests – to be obstructive and “completely meaningless.”

“If anyone wants to suggest that I, or anyone else who's gotten to this stage hasn't thought long and deeply about this, and if they've made the request, hasn't done it with information – or at the end of the day, with conviction – they're crazy,” Jewett said. “What do people think we do when we're sick in bed?”

A senate committee heard testimony in January that would make three key changes to the law.

1) It would allow patients to request a prescription using telemedicine, rather than in-person visits. 2) It would remove the 48-hour waiting period. 3) It would expand explicit legal protections beyond physicians to other healthcare providers involved in the process, such as pharmacists.



The eyes have it! Turned down for Guide services, she now works in the program

By Deborah Alecson, FEN Coordinator

Throughout my life, I have had an acute awareness of mortality and our culture's death denial; in particular, that of Western medicine.

There was the mangled birth (then welcomed death) of my first child in 1989, born with irreversible brain damage due to medical malpractice during labor – then the fight my late husband and I had with the hospital to allow her to die.

There was my husband's diagnosis of metastasized pancreatic cancer in 2000 and the insistence of oncologists that he endure brutal and futile chemotherapy until he had the courage to stop and receive hospice care in his final months.

There was my mother's unexpected suicide in 2013 at the age of 86. Finally, by 2017, I developed eye diseases that greatly impacted the quality of my daily existence.

This condition made me see double – the world around me a complete distortion.

I had to retire early from teaching undergraduate courses in the field of thanatology. After months of seeing local ophthalmologists who could not figure out what was going on, I found one who diagnosed pre-retinal fibrosis in both eyes. This condition made me see double – the world around me a complete distortion. Glaucoma in my left eye, diagnosed earlier and caused by a condition called pseudo exfoliation (in both eyes), required an arsenal of eye drops that only increased over time.

I entered a phase of life that required letting go of activities and identities in the world at large by redefining who I was as a person, someone not able to do and struggling to be. The eye specialists covered by my insurance were limited with the best outside the network. My son (born 14 months after the death of my daughter) moved out to Colorado the week of my diagnosis to continue his glorious professional ascent. I was alone, and while I was not going blind, I had lost my vision.

I knew about Final Exit Network from my

GLAD SHE WAS REJECTED

work, and in May 2018, I became a member. Soon after, I applied for Exit Guide services. I was certain then – and am certain now – that I would not want to live should I be blind, an assertion I have made to my son and all my friends.

Also, while I threw myself into “vision therapy” to rewire my brain to see straight, I wanted reassurance that should therapy fail and surgery of some kind was not an option, I could end my life peacefully with guidance from FEN.

Seemingly, within hours of reaching out to FEN, I heard from what I have since learned is a “coordinator.” I was impressed by her kindness and lack of judgment.



Deborah Alecson

She told me to write a personal statement about my condition and why I was applying to the Exit Guide Program, and to get copies of my medical records from the doctors I had been seeing for the eye diseases. I got these documents to her, and soon after, I had a phone interview with someone from the organization, who also was kind and not judgmental.

My application was rejected by the Medical Evaluation Committee (the final step in the process). I was more impressed with this outcome than disappointed. The fact of the matter was, I was able to drive with my left eye covered and a corrective lens for the right – *it was not time to check out.*

Four years later, after four eye surgeries (thanks to becoming eligible for Medicare) and months of pain from uncontrollable eye pressure – then the ultimate, the removal of my left eye last June – I am able *to do* and *be* in the world.

What I am *doing* is being a FEN coordinator for FEN Exit Guide services. It is something I would not have been able to do had my application been accepted!



Cancer 4x is 1x too many

By Jay Niver, FEN Editor

Carole Campana beat different cancers three times before a fourth case was diagnosed. Enough was enough, so she applied for FEN Exit Guide services and was approved early in 2021.

She has a nexus with FEN besides joining the network long ago: FEN's new general counsel, Boston attorney Pam Bankert, calls Carole her best friend "for sure, 100 percent."

Pam was one of Carole's students when she attended college over 40 years ago. Much later, the prof schooled herself in RTD issues to teach a graduate course in aging and dying. She discovered FEN, and in 2014, she learned from Pam of a meeting of the World Federation of Right to Die Societies – *and off they went to Chicago.*

"She didn't have to talk me into it," says Carole. "I was all hot to go. We had a great time."

Carole, 82, is willing to share with FEN members, and with the public, the reasons for planning her own exit – which isn't imminent, she says: "I have set no date, and there is no rush. But I'm sort of feeling like, the sooner the better."

Her cancer looms ominously with surgical, radiation, and chemo therapies available – that carry a panoply of harsh side effects she refuses to suffer through.

"The (last) diagnosis was so dire, I got them to write it down and I sent it to the FEN people," Carole explains. "I never thought they would accept me once I refused medical help, but not so! They're so wonderfully open and accepting of more than one way to be. You don't have to promise to die within six months."

For now, her cancer symptoms are absent, but another constant, unrelated problem makes "quality of life" an oxymoron.

"I have chronic dizziness that has nothing to do with cancer," Carole says. "It's horrible because it's hard to stand up and move. I feel like I'm always going to fall."



Carole Campana catches some rays outside of her Chicago hotel room in 2014.

'I'm so grateful to FEN ... for not leaving me at the mercy of the hospital or the docs or people who have no right to be in the middle of my life.'

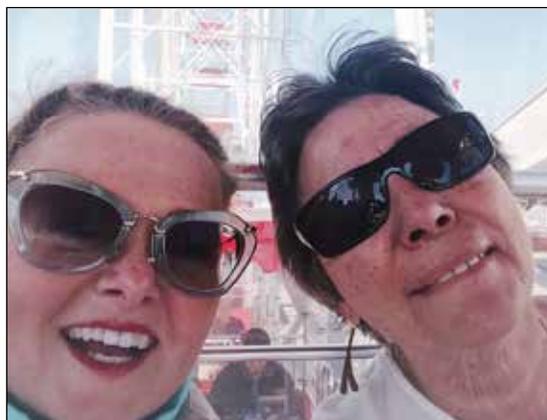
I do fall a lot."

Carole has no family for support, which also means "less people to make trouble" (about her decision), she says. "I have a family of friends that is very tight ... I have been a psychotherapist for decades, and ending my work with patients I have known for years has been almost as hard as leaving beloved friends ...

"I'm so grateful to FEN for giving me choices, for not leaving me at the mercy of the hospital or the docs or people who have no right to be in the middle of my life.

"My remaining time will be lighter, knowing that I remain in control."

Editor's note: The preceding story was written last fall. Carole Campana concluded her life well-lived on Oct. 26 in her New York City home.



Pam (l) and Carole at Chicago's Navy Pier.



• A CAUTIONARY TALE • ADs are under attack

By Michael James, FEN Member

Judith and Dick Magney had a well-crafted, valid Advance Directive (AD), but it took a courageous California attorney to defend it against a County Adult Protective Services Department and County legal establishment.

Although probate codes are different in every state, there are important lessons to be learned from this case.

Dick Magney, a devout Christian, was hospitalized in February 2015 with multiple medical conditions that his primary-care physician stated made further treatment futile. He clearly said he wanted palliative care only, and he did not want medical treatment to prolong his life.

His Advance Directive (AD) made crystal clear his desire to not prolong his life with medical treatment that would provide no benefit. The AD appointed his wife, Judy, as his healthcare agent (surrogate).

Unfortunately, an Adult Protective Services (APS) nurse, acting on an unsubstantiated report of “caretaker abuse,” inserted herself into Mr. Magney’s care, claiming he wasn’t competent and could not refuse care.

This nurse’s position was supported by the Humboldt County legal establishment, which went

to court to revoke the Advance Directive and appoint a public guardian instead of Judy Magney. The county withheld evidence from the trial court that Mr. Magney’s primary care physician’s clinical assessment

‘The county was running over these people like they were speed bumps.’

found him competent and stated palliative care was the appropriate treatment.

Fortunately, attorney Allison Jackson agreed to represent the Magneys *pro bono* when she learned of the egregious and unsubstantiated claims the county and APS were raising to revoke the AD.

Jackson said she “felt



Dick and Judy Magney in early, healthy years.

obligated to take the case. The county was running over these people like they were speed bumps.”

Dick Magney died in October of 2015. He was 74.

In October 2016, the California Appellate Court ruled in the Magneys’ favor, delivering a stinging rebuke to those who had tried to revoke Mr. Magney’s Advance Directive.

“The Health Care Decisions Law protects the most personal of decisions and an adult’s choice to die on his or her own terms,” the court said. “One of the most important features of an Advance Directive is that it remains operative.

“If and when the patient loses capacity, we cannot subscribe to a scenario where a governmental agency acts to overturn the provisions of a valid Advance Directive by presenting the court with an incomplete discussion of the relevant law and a misleading compendium of incompetent and inadmissible evidence and, worse, by withholding critical evidence about clinical assessments and opinions of the primary physician because that evidence does not accord with the agency’s own agenda. No reasonable person, let alone a governmental agency, would have pursued



Allison Jackson

such a course.”*

In late 2016, Mrs. Magney received \$1 million and Jackson’s firm was awarded fees of \$211,000.

According to attorney Jackson, these are lessons to be learned from the Magneys’ experience:

1. She recommends that an Advance Directive not only name a surrogate and at least one alternative agent, but also specify any persons who you do *not* want to represent you. In her experience, unexpected challenges to ADs from relatives and well-meaning but ill-informed friends were problems that could have been avoided.

2. When selecting an attorney to prepare your Advance Directive, choose someone who has experience dealing with ADs in your state.

3. Lastly, Jackson has this final thought for those who want to control their final days: “Think carefully before deciding to go to the hospital, as that’s the place where it’s easy to lose control of decisions.”

*Court of Appeal of State of California First Appellate District Division 10/24/2016 – Humboldt County Adult Protective Services v. Superior Court of Humboldt County and Judith C. Magney, Superior Court No. CV150159 p.28



Where there’s a (living) will, there’s a way

By Janis Landis, FEN Member

Here’s a scenario that occurs every day in this country:

A person has a car accident while on vacation. They are rushed to the hospital. The spouse knows there is an Advance Directive and Surrogate Designation form. But who packs the forms when going on vacation?

If you’ve signed up for our free member benefit, enrollment in the U.S. Advance Care Plan Registry, the documents are just a phone call, email, or fax away. And medical personnel can look it up directly, with just basic information, if you are alone and incapacitated.

Included in your FEN membership is free access to all the benefits of the Advance Care Plan Registry (ACPR, formerly known as the Living Will Registry).

FEN directly pays ACPR a fee each year to cover all our members. Obviously, we must think this benefit is pretty important. And it is: because the most painstakingly crafted Advance Directive, and the most thoughtfully selected surrogate, are of no use if your documents aren’t available in a medical emergency.

Perhaps you are confident that you have copies of your forms handy and don’t need the “bells and whistles.” But what happens if you decide to update your AD or your surrogate? Will you remember to send it to your doctors, lawyer, surrogate, etc.? How will individuals be sure they have the latest copy?

With the registry, you can complete or update the correct state forms and have them readily accessible to all who may need them.

And most importantly, the copies will be available when you need them most and are least likely to have them: in sudden emergencies.

I recently spoke to Katie Urban, a client manager at ACPR. She described the many different situations that ACPR responds to daily.

One individual had a heart attack while traveling in India. A quick check on-line retrieved all the necessary documents.

Another individual, only 30 years old, was driving in an unfamiliar rural area when he suddenly experienced chest pains. He was able to find a local clinic. Immediately, the staff was able to reach his AD, know what type of treatment he wanted, and who the surrogate was.

April 16 is Health Care Decision day. Make the decision to get your documents registered before then so you can make your summer plans with peace of mind. Get your friends and family to register too. (Of course, with a FEN membership, they’ll get free registry access.)

And hey, there’s an app for it too!

You can’t take it with you

The gifts that members and friends bequeath to FEN are usually more than half of every dollar of FEN’s budget.

Please remember us in your will, or name FEN as a beneficiary in your IRA or other financial product. It is easy to do and requires no legal advice.

All you need is our tax ID (80-0119137) and address: Final Exit Network, POB 10071, Tallahassee, FL 32302.

If you have any questions, just call us toll-free at 866-654-9156. We’ll help you through the easy process to leave a gift for FEN.

Ruth Gordon and Bud Cort portrayed Harold and Maude in the 1971 film.

The police accused my mother of assisting a suicide and waved that handkerchief in her face until she was in tears.



Hollywood helped inspire her exit

She 'knew' when she was child, and ancestors put it in her DNA

A very close friend who I had clued in to my exit planning asked me when I had made that rather unusual decision. I explained that I had joined the Swiss organization Dignitas several years ago after a fourth major surgery, where my surgical team of geniuses tried again to reinforce my failing spine.

At that time, I knew the damage was irreversible and a downward slide was inevitable. I loved life, but ending up almost paralyzed from the neck down, in pain, and in diapers sitting in a wheelchair just waiting for Mephistopheles did not appeal to me.

My mother had spent her final three years in a Skilled Nursing Facility with her body falling apart, but her brain sharp as a tack, so I had a front-row seat to how life in even the best of facilities can be much worse than death.

Full disclosure: Unfortunately, my planned vacation to Switzerland did not pan out. I had waited too long to make my case and was in too much pain to make that journey, even first class supported by friends.

When my friend asked me that question recently, it got me thinking. No, it was not the many surgeries that informed my decision. I knew before – *way before*. The 1971 movie *Harold and Maude* was one steppingstone backwards. When Maude drank champagne and danced with her very young lover, Harold, on her 80th birthday – just before she revealed that she had taken

enough pills to end her life before midnight – I knew.

I knew when I was a child and my aunt, who was dying of cancer, saved her pain medication in a lace handkerchief until she had enough to end her suffering. The police accused my mother of assisting a suicide and waved that handkerchief in her face until she was in tears. I knew in my soul that something was terribly wrong.

Why would anyone insist on keeping someone from ending their unbearable pain? We had taken our suffering dog to the vet. Why were pets treated better than people? It made no sense to me.

Then I realized I knew way before that, even. My first American ancestors were Reformation Protestants who were willing to brave the Atlantic Ocean, the wilderness, wars, and endless other hardships just for the right to think for themselves and make choices about their own future. It was in my DNA – *I had always known*.

Maude said 80 years were enough to live a complete life, if you grab it by the horns. She was right. I am 83, and it has been a great ride!

Editor's note: The author was a FEN member who used Exit Guide services to exit last summer and wished to remain anonymous.



FEN Volunteer Extraordinaire

By Carol Ballou, FEN Member

On Nov. 3, 2021, with the guidance and support of an End of Life Washington exit guide – and in the presence of his son, daughter and partner Sue – Tom Tuxill died. He had been diagnosed with terminal brain lymphoma in September.

Tom's death marks the end of a life lived with enthusiasm and compassion. We in FEN who had the privilege of volunteering with Tom learned and benefited in countless ways from his wisdom and commitment.

My own career as a FEN volunteer began in November 2016 when I joined the Medical Evaluation Committee (MEC), which Tom had chaired for the previous five years.

At his suggestion, I became MEC chair in January 2018. Tom told me I would have his undying gratitude if I would consider taking over the role; I will always be grateful to him for the steadfast support, astute guidance, and warm friendship he gave me in the years that followed.

Tom became interested in the right to die (RTD) when he was diagnosed with systemic large-cell lymphoma in 1997. He retired as an ophthalmologist and underwent intensive treatment over the years when the disease reoccurred. Given the poor long-term prognosis, it behooved him to educate himself about peaceful methods of self-deliverance.

Tom began with FEN in 2010. He was truly *Volunteer Extraordinaire*, serving not only as MEC chair for six years, but also as a Senior Guide for seven years, board member for eight years, and senior medical advisor. Finally, he was as an invaluable member of numerous committees. His tireless RTD advocacy shines as a bright light for those of us who will continue this work in his memory.

In our last conversation, Tom spoke about the peace of mind he felt, having provided a compassionate presence at the deaths of clients, and having learned what to expect, and what his family might expect, at his own exit.

It was Tom's nature to pursue interests passionately, and FEN benefited hugely from this trait. However, FEN wasn't the only recipient of Tom's dedication. He also loved family and friends, fishing, flying, and football. He had an appetite for life and adventure. His life illustrates so beautifully how preparing ourselves for death frees us to embrace life more openly.

I will miss Tom deeply. At the same time, I find comfort and inspiration in the story of his life and death.

Tom's strengths as a fellow volunteer and friend were legion, and it's impossible to put into words the quality of our conversations over the years. He was unfailingly generous and patient, and always seemed to have time to engage and lend support and guidance.

He never made me feel I was interrupting, despite my myriad calls about MEC issues. His calm, gracious problem-solving approach, combined with the depth of his experience and knowledge, were invaluable. I always ended our conversations feeling encouraged and glad I had phoned.

Tom was an inspirational person for me and for all of us who had the privilege of knowing him. He made us all better people.

FEN President Brian Ruder wrote the following in a memory book FEN volunteers compiled for Tom before he died:

"Tom, you are and always have been my guiding light when it comes to FEN. Your compassion for the clients and the volunteers has helped me keep things in perspective. Your great desire to find the best in everyone is something special that I have always envied.

"You are the best volunteer that FEN has ever had. Your dedication and support to our organization is the foundation of our changing culture. I appreciate all of your support, especially when it was a hard choice. I will remember you as one of the best I have ever had the opportunity to work with. Thank you."

♪



Dr. Tom Tuxill

Good Endings Book Club



This Is Assisted Dying

By Stefanie Green, MD

Reviewed by Jim Van Buskirk

“What if you could decide, at the end of your life, exactly when and where your death would take place? What if, instead of dying alone, in the middle of the night in a hospital bed, you could be at home at a time of your choosing?

“You could decide who would be in the room with you, holding your hand or embracing you as you left this earth. And what if a doctor could help ensure that your death was comfortable, peaceful, and dignified?

“What if you could plan a final conversation with everyone you love? You might never look at death the same way again.”

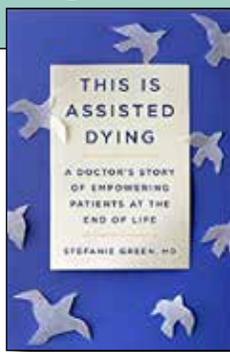
This moving memoir’s very first words capture its sensitive tone and courageous intent. Stefanie Green, a maternity doctor for over 20 years, changed course in 2016 soon after Medical Aid in Dying (MAiD) became legal throughout Canada:

“Not unlike my role in maternity care, my job in MAiD is to stay focused on what patients need, listen for the intentions, understand their goals, and help steer them and their loved ones through what I hope can be a slightly more empowered transformation from partner to caregiver, from person to patient, from life to death.

“At both ‘deliveries,’ as I call them, I am invited into a most intimate moment in people’s lives.”

The book chronicles her first year providing MAiD in and around Vancouver Island, British Columbia, “a region that has turned out to have the highest percentage of assisted death ...worldwide.” Dr. Green frankly recounts her initiation into this new territory: from initially wondering what to wear, to what to say in the patient’s final moments, to lack of billing codes.

Sometimes encountering reticence from other



physicians, nurses, and pharmacists, she compassionately observes, “It seemed every person I met was trying to find their footing in this very new field of care.”

And she struggles to balance her own personal boundaries: “Just because I want to help doesn’t mean I should, and just because I can help someone doesn’t mean I must ... There is law, there are practice standards, there are clinical opinions, and there are personal limits.”

Vividly recounting each unique case, she deftly describes in detail the specifics of her experience with her patients and their families. She acknowledges her successes and expresses remorse at cases she might have handled differently. She astutely identifies the interplay “between the realms of clinical decision-making and legal interpretation” to conclude that “politics, unclear laws and fear were all playing a role.”

As a founder and president of the Canadian Association of MAiD Assessors and Providers, she is justifiably proud that the group now numbers over 400 members nationwide. As another indication of Dr. Green’s sensitivity, in addition to valuable resources, the book ends with a list of her patients’ final words.

Despite differences between Canada and the United States, and between MAiD and Final Exit Network’s support services, the situations’ many similarities render this personal, powerful memoir an important contribution to the controversial conversation about hastening death.

This Is Assisted Dying: A Doctor’s Story of Empowering Patients at the End of Life
By Dr. Stefanie Green • Simon & Schuster
March 2022 (304 pages)

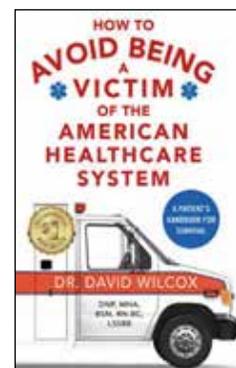
... Avoid Being A Victim ...

By David Wilcox, MD

Reviewed by Gary Wederspahn

This book is a powerful self-defense manual for patients and their loved ones dealing with the highly complex and exploitative American healthcare system. It is especially useful for those who are facing end-of-life issues and challenges.

The author, Dr. David Wilcox, is an extremely well-qualified insider who courageously pulls no punches when exposing the many ways people are manipulated and taken advantage of when they are at



their most vulnerable. For example, he bluntly points out, “The cold fact is, the driving factor for most healthcare business models is money instead of health.”

More importantly, he provides many practical tips and common sense advice that empower users of the healthcare system to actively (and proactively) regain some control over the costs and outcomes of their care. That is a sense of urgency and choice that motivates most of us in the right-to-die movement.

Still, his aim is not to create an adversarial confrontation between patients and their paid caregivers, but to promote partnership and teamwork to help make the system perform better for their mutual benefit.

Dr. Wilcox is a doctorate-level nurse who also holds a Master’s in Health Administration with 28

years’ healthcare experience working as a bedside nurse, hospital administrator, and in healthcare information technology.

His writing style is very simple and reader-friendly. The book is a quick read, but I suggest that it be kept handy for reference before a healthcare crisis has to be faced.

The whole book is relevant when dealing with end-of-life situations. It is not merely critical of the system, but points out ways it can be improved.

How to Avoid Being a Victim of the American Healthcare System: A Patient’s Handbook for Survival

By Dr. David Wilcox • Self-published

June 2021 (185 pages)



One point of view –

Rational suicide – a thoughtful death

By Brian Ruder, FEN Board President

Ten states and the District of Columbia have given official acceptance to the concept of a rationally hastened death. They all permit Medical Aid in Dying (MAiD) that allows a terminally ill person to die when they choose, using drugs prescribed by their doctor.

It then seems “rational” to assume that a person who is suffering from irremediable medical conditions and wants to hasten their death can also be rational. The patient is terminal, just not necessarily six months from dying.

But many states have laws that require police to take people for a mental examination if someone reports that they are contemplating taking their own life. The assumption is that if you want to hasten your death, you cannot be rational.

A rational person is one who makes decisions based on the best information available, rather than on emotion. While none of us has the experience of dying, many of us have experience seeing loved ones die after suffering for long periods of time.

All people approved for Final Exit Network services are rational and thoughtful. They all have serious medical issues. Those who choose to hasten their death do so for their own reasons.

Maybe their quality of life is becoming unbearable to them. Or they fear they may have to move into a nursing home. They may not want to be a burden to their families or waste money trying to stay alive.

They all are thoughtful and want to control their

What seems irrational to me is believing that suffering is acceptable, regardless of how severe or how long it may persist.

death as best they can. These reasons, among others, seem rational to me.

No one wants to die before they must. Most of us are uncomfortable thinking about dying, because there are so many unknowns, and it makes us anxious. And if you want to hasten your death, there is no perfect time.

You are always going to leave some life on the table. But for FEN clients, the cost of leaving that time on the table is much less than the cost of worrying about the things that might happen, or the suffering they might endure. This logic seems perfectly rational.

What seems irrational is learning that you have dementia and will lose competence at some point in the future – then deciding to live with dementia for years to come, instead of hastening your death legally and peacefully while still of sound mind.

What seems irrational is believing that suffering is acceptable, regardless of how severe or how long it may persist. What seems irrational is not at least exploring the legal options for managing your death on your own terms.

I plan to deal with my death in a rational and thoughtful way – for myself and for my family and friends.



'COMING OUT' IN DEATH

OBITUARY TRUTHS REVEAL RTD EXITS

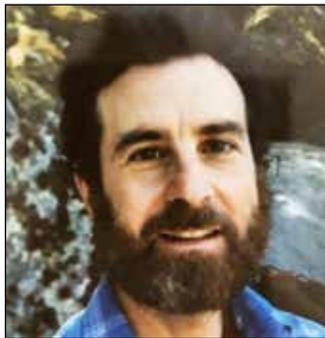
Societal change may seem slow, but we are seeing a broader understanding of and appreciation for choice in dying. In the vanguard are those who proudly share in their obituary that they chose to exercise a right-to-die (RTD) option to end their life.

It certainly isn't common, but we are seeing more people come out of the shadows in this public manner, and it is the sort of statement that

can have quiet ripple effects.

Theory and discussions of personal liberty are one thing, but when family, friends, and neighbors read about a person they knew – about Bob Lobell – the choice becomes real and tangible, and not so “out there,” because people realize that these choices are being made right here, wherever “here” happens to be.

– Lowrey Brown, FEN Director of Client Services



Bob Lobell

January 29, 1945 – September 16, 2021

Robert “Bob” Lobell, born 1/29/1945 in New York City to father Benjamin Emmanuel Lobell and mother Claire Iris Encherman, died at his Nevada City home on September 16, 2021.

Bob chose to conclude his life in order to avoid the unbearable effects of Parkinson’s disease.

Before obtaining college degrees in anthropology (Cal State L.A.) and human development (CCNY) Bob’s work experience included: being a college mailman; caring for experimental lab animals; pathology lab technician (autopsy assistant); radio DJ and public affairs interviewer (WNMU FM, Marquette, Michigan); legal assistant; and academic tutor.

Bob settled in California around 1988, when he was hired to teach at Sunflower School. His spouse Jennifer Long’s children attended the school, allowing Bob and Jen to get to know each other before they married in 1992.

Several years later, Bob began work as a paralegal with Legal Services of Northern California, specializing in elder law, working closely with Nevada County Adult Protective Services regarding issues involving elder abuse. Aside from teaching, Bob’s interests included politics, music, organic gardening, academic tutoring, and in particular writing letters to the GV Union Newspaper editor. Bob was also a certified mediator.

Bob is survived by his wife and visual artist Jennifer Long, sister Judith Rachael Lobell, 4 children: Darci Thibodeau, Rose McCollough, Lucia Cortright, and Tahoe Arbogast, as well as 13 grandchildren and 10 great-grandchildren, all of whom he cared for as his own. **And thanks to FEN, the Final Exit Network, for its support of choice in dying.**

(Editor: emphases added)

THE BACK PAGE

A COMPENDIUM OF RIGHT-TO-DIE WORLD NEWS

United States

• **Delaware** – A bill allowing Medical Aid in Dying (MAiD) cleared a Democrat-led House committee by a single vote in January, paving the way for possible consideration by the full House. All Republicans voted against it.

Similar bills have been repeatedly introduced by Democrat Paul Baumbach since 2015, but none has received a floor vote.

Supporters and opponents debated the bill during a three-hour committee hearing. Critics include the Delaware Healthcare Association, which represents the hospital industry, and the Wilmington Catholic Diocese. Members of the medical community and advocates for people with disabilities are split on the issue.

The state Medical Society traditionally opposed the legislation, but adopted a position of “engaged neutrality” late last year.

• **Massachusetts** – A new wrinkle in a proposed MAiD law is intended to ensure that financial factors do not influence a dying person’s request for help.

A recent provision added to one bill ensures that people who would financially benefit from the death of the patient, such as family members, are prohibited from witnessing the decision to ask for a prescription.

Two bills introduced last year reopened the conversation around aid in dying. Seventy percent of Massachusetts residents support MAiD, according to a 2020 poll conducted by *The Boston Globe* and Suffolk University. In the same poll, 74 percent said they would want doctors to stop treating them if they had an incurable disease and were in “terrible pain.”

The legislature has rejected multiple attempts to introduce “death with dignity” bills over the years.

Colombia

Two Colombians became the first non-terminally ill persons to take advantage of their country’s euthanasia policy early in January.

Victor Escobar, 60, and Martha Sepúlveda, 51, died one day apart. He suffered from end-stage chronic obstructive pulmonary disease, as well as other conditions. She was stricken with amyotrophic lateral sclerosis (ALS). Both were devout Catholics.

Escobar had fought two years for his right to euthanasia in the face of opposition from doctors,

clinics, courts, and the Catholic Church, which categorically opposes aid in dying.

Colombia de-penalized assisted death in 1997, and in July 2021 a high court expanded the “right to a dignified death” to those with “intense physical or mental suffering from bodily injury or serious and incurable disease.”

That allowed Sepúlveda to schedule her death last Oct. 10, but an 11th-hour decision by her clinic cancelled the procedure. A judge revoked that suspension Oct. 27, and she was able to reschedule her date for euthanasia.

Austria

Austrians are now legally allowed to seek aid in dying after a new law took effect on Jan. 1.

A requesting patient must be either terminally ill or have a permanent, debilitating condition. They will also have to consult with two doctors and, depending on their condition, must wait between two and 12 weeks to reflect on their decision before they may access a lethal prescription from a pharmacy.

Under the new law, it will still be illegal to actively assist in someone else’s suicide, and minors and people suffering from mental-health issues will not have access to Medical Aid in Dying.

Italy

The country’s constitutional court was to rule Feb. 15 on the validity of two referendums to legalize euthanasia and cannabis. Both issues were green-lighted in January when a court validated signatures gathered in public petitions.

Right-to-die activists secured over 1.2 million names calling for a referendum to decriminalize euthanasia. For contrast, marijuana advocates gathered 630,000 signatures in their campaign.

The euthanasia referendum would abolish a clause in a 1930 law that punishes the homicide of a consenting person with up to 15 years in jail.

The movement received a boost last November when Italy’s first medical aid-in-dying case was authorized by the ethics committee of a regional public health authority.

MAiD is a divisive issue in Italy and faces strong opposition from the Vatican.



FINAL EXIT NETWORK
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Are 2 heads better than 1?



Having two heads didn't work out so well in the campy sci-fi flick *The Incredible Two-Headed Transplant*.

By Althea Halchuck, FEN Surrogate Consultant

“Putting both siblings, who often disagreed in their lives, on equal footing in the healthcare directive, was asking for trouble.”

That's the verdict offered by attorney Carolyn Rosenblatt.

People often ask me about the wisdom of naming two people as co-surrogates in their Advance Directive (AD). This is not a good idea – though people feel confident their children would be perfect candidates.

In some states, you may pick more than one, such as choosing two children, or your spouse and a child as co-surrogates. Check your state, because it may not be legal to have more than one surrogate or power-of- attorney for healthcare. Laws vary by state, so make sure it's even possible before you create a problem that legally cannot exist.

You can, however, name any number of *alternate* healthcare agents. Regardless of what is permissible, understand that medical staff prefer just *one* person making your healthcare decisions. Healthcare providers want a single decision-maker: It's most efficient in an emergency.

Besides, if *two* people are in charge, there is always room for some disagreement, and they could give conflicting instructions to medical staff. It gets too confusing and cumbersome when caregivers have to track down and consult with two or more people, even if the surrogates are on the same page regarding treatment.

Medical teams need answers and don't have time to locate two or more surrogates or wade through family disputes.

People often fear that if they don't choose both or all their children as surrogates, someone will be hurt. It is more likely that while your children love you, they would rather not make life-or-death decisions. It would be better to have that conversation with them long before anyone is expected to follow your AD and feel uncomfortable or reluctant to act.

It would be best if you have an alternate, and you could have a second child in that role. If they are close sibs, they can collaborate and be in on all your conversations. There should be no question about what you want if, for any reason, #1 is not available, and #2 must step in.

The most important goal is to choose a strong surrogate who will carry out your wishes. The FEN website has a list of qualities you should seek in whomever you name as your surrogate.

***Medical teams need answers
and don't have time to locate
two or more surrogates or
wade through family disputes.***
