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An Advocate by Accident

**A near-fatal college mishap launched
'BJ' Miller on a meteoric crusade to change
how we view and deal with death**

By Jay Niver, FEN Editor

Dr. Miller in his 2015 TED Talk

If you knew him in 1990, you'd never guess that Bruce Miller, Princeton sophomore, would give [a TED Talk](#) to be viewed more than 14 million times. Or that he would be [interviewed by Oprah](#) and [NPR](#), and be featured in an 8,000-word [New York Times Magazine story](#).

No, at the age of 19, Miller was a typical carousing undergrad who decided to climb atop a parked trolley car at a time in the morning when nothing good ever happens.

Nothing did. He was zapped to the tune of 11,000 volts, nearly died, and ended up losing both legs below the knee and his left arm at the elbow.

His physical loss was a potent gain for anyone who cares about how we die, what we think about death, and the state of U.S. healthcare in general – especially how we regard and treat people facing crucial end-of-life planning and decision-making.

Miller, now known as "BJ," went on to become a hospice and palliative care physician. When it came to dying, he had almost "been there, done that," so it gave him unique insight into what his patients might be feeling and confronting. And, as a triple amputee, it gave him first-hand experience in the personal and societal hurdles that challenge disabled people.

MILLER continued on page 2

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“ ... I’m very supportive of the (MAiD) law and of the idea and spirit behind it. Where it gets a little tricky is, I wish the other pieces of the puzzle were advancing at the same time. ”

MILLER *continued from page 1*

Dr. Miller has countless media outlets – and high-profile speaking engagements – to spread his constructive but critical assessment of the American medical system. He is a charismatic figure who speaks not with bombast or statistics, but with sincerity and expertise in an affable, thoughtful way.

FEN discovered that when we worked into his schedule for a Zoom interview in late September. BJ answered our questions about myriad topics including Medical Aid in Dying (MAiD), for-profit hospices, the pace of change, and the state of U.S. healthcare.

Hospice has traditionally been devoted to the idea that good palliative care – and caring attention – can make dying peoples’ lives worth extending for their final weeks or months. Planning an “exit” in advance was anathema to many hospice workers and supporters.

Miller led the iconic Zen Hospice Project in San Francisco for six years. He came away recognizing that “There are pains that come at the end of life that can’t be treated, that can’t be mollified. In other words, there are sufferings that our bag of tricks won’t reach.

“I’ve been involved with patients who passionately wanted to have this option (MAiD) for themselves, and I’ve been in California before and after the law and seen the difference,” he said. “In a relatively narrow frame, I’m very supportive of the law and of the idea and spirit behind it. Where it gets a little tricky is, I wish the other pieces of the puzzle were advancing at the same time.”

Medical Aid in Dying is coming of age, and Miller cites some reasons.

“The conversation is maturing,” he said. “It’s been in the ether for a while now, and so I suppose that it’s less of the shock value of the Kevorkian days, and more of a thoughtful conversation in various circles ...

“It’s no longer a secret, if it ever was, that the



BJ tells his story to Oprah Winfrey.

medical system in the U.S. has some severe limitations, some serious problems of its own, and that medical science can’t fix everything. And even if it could, it’s such a messy system that people struggle to get magical care, even if it existed. So, another big piece of this is disillusionment with healthcare and with medicine’s capabilities.

“I think a third piece of the puzzle is just the volume of people who are aging – living with chronic illness, living with disability, living with things that on some level they can live with, but it’s getting increasingly difficult.

“So, the idea (to them) is not so abstract. A lot of us just look within our own lives, and we see people who might actually say, and endorse the idea that there are certain fates worse than death. And a lot of people are living those fates in this country.”

Miller was asked about the overwhelming trend toward for-profit hospices.

“The bottom line of a for-profit organization is a little bit different,” said BJ, “and that can erode the level of care ...

“When I started in this work, 17 or 18 years ago, you could unequivocally recommend hospice to someone ... the experiences were almost uniformly wonderful.”

Now, he said, when

‘A lot of us just look within our own lives, and we see people who ... endorse the idea that there are certain fates worse than death. And a lot of people are living those fates ...’



Dr. Miller talks with FEN editor Jay Niver in late September.

***‘A lot of our neuroses, our anxieties,
stem from perpetuating this idea
that life and death are somehow at odds ...
it’s clear that this is a package deal.’***

he advocates for hospice, “I’m sadly all too aware that someone might listen to me, sign up for hospice, and have a really bad experience. And that scares me and saddens me greatly ...

“The growth in the industry has come at some expense of quality, and it does seem that a lot of that breakdown does pivot around the for-profit versus the not-for-profit status. Not entirely, of course ...

“By and large, still, the satisfaction data around hospice is profoundly good, and people should generally have very good experiences – but it’s rickety, that’s true.”

Changes in hospice may not be for the better, so we asked BJ if he’s more upbeat about changes in our cultural approach to death, and improvements in the U.S. healthcare system – which he called “one of the crummiest.”

“We have incredibly talented scientists and clinicians. We have a lot of strength within that wobbly system, but the system itself is dramatically underdeveloped; woefully inadequate,” he said.

Miller said American healthcare has some huge “structural and systems issues. I would love to see healthcare redesigned from the bottom up, taken down to its studs ... It’s so overdue, the world has changed; the system does not work.

“I’d really love it if we could evolve as a society to understand that death is part of life, not this thing that robs us of life ... but rather this very natural part of life ... I feel that a lot of our neuroses, our anxieties, stem from perpetuating this idea that life and death are somehow at odds ... it’s clear that this is a package deal.”

Is Miller frustrated about the pace of progress?

“Absolutely! I mean, Jeez Louise! On some levels, I do think the conversation around MAiD is maturing, is less exotic than it was 10 years ago. And similarly, I think the conversation on end of life, palliative care, the limitations of

healthcare – those conversations have matured too. In this way, I think, it’s getting better.

“I do see more substantive changes at policy levels. Do I see more communities developing end-of-life caregiver support programs, or building places to die? No. It is incredibly slow, but I also have to remember that this subject didn’t start with you or me.

“It’s been around awhile, and people who have gone before us have been dancing this dance for a long time. Things were even more backward 20 years ago.”

In an upbeat mode, BJ said, “There is progress, and it’s slow, agonizingly slow. But I also have this feeling that there can be a moment or two in time, an inflection point at the policy level, at the social level, where things progress in a little bit of a leap.

***‘I would love to see healthcare redesigned
from the bottom up, taken down to its studs ...
It’s so overdue, the world has changed;
the system does not work.’***

“And it’s not so much whether to have a MAiD law, but rather a matter of refining that law and making it more functional, more thoughtful. So it’s not whether we ask for this option, but how we do it.”

(Editor’s note: Dr. Miller is the co-author of [A Beginner’s Guide to the End – Practical Advice for Facing Death and Living Life](#) and founder of [Mettle Health](#). Additional excerpts from FEN’s interview with BJ be posted on [The Good Death Society](#) blog.)



Navigating an uncertain year

– *Finances remain sound despite challenges* –

FROM EXECUTIVE DIRECTOR MARY EWERT



I'm proud to report that despite the pandemic and a legal challenge in Minnesota, FEN's finances remain solid. FEN is unique in what we do. It's critical for us to reach more of the people who need our services and/or want to support us. There are many more who would join with us if only they knew about us, and we plan to reach out strategically to those people.

Our ability to meet members' needs, despite the extraordinary challenges of COVID and the new legal case in Minnesota, gives us confidence to further expand our services and outreach. Your support remains critical in helping us achieve that and move forward in support of establishing the right to die as the civil liberty of the 21st century.

During the current period, the FEN Board of Directors is committed to three goals:

- Successful completion of our first external audit.
- Development of FEN's fundraising capacity through outreach to new grantors and donors.
- Development of a broad plan to bring FEN's message to a wider public audience.

Be assured that we run a tight FEN ship. We work hard to ensure that every dollar supports the work we do to serve our clients and advance the cause of end-of-

life liberty. Thanks to members and donors, we safely navigated the choppy waters of 2020-21. With your help, we will continue to grow and thrive.

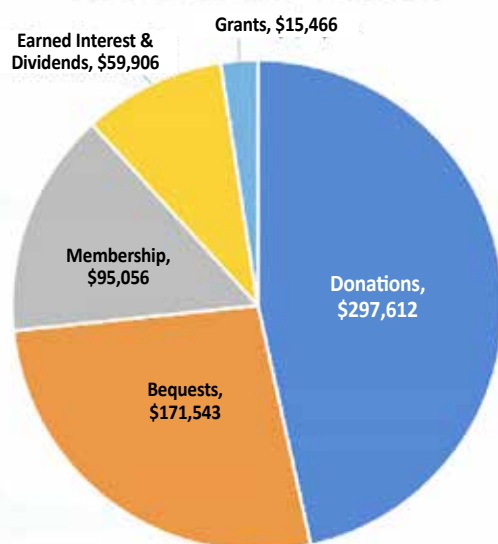
As to revenue, donations, memberships, and bequests covered expenses, and we had a good return on investments. Aware that FEN is self-insured, our treasurer is an active steward of these investments (our way to meet unanticipated expenses, as this year with legal costs of the Minnesota case). We will continue to build our portfolio for an even stronger future.

On the expenditure side, travel costs were down. Exit Guides have resumed travel, so we expect to see higher Guide Services costs this year. Even when travel was challenging, our volunteer coordinators remained busy fielding calls and answering questions, an often-unrecognized service FEN provides. (See story about longtime coordinator Ann Mandelstamm on page 9.)

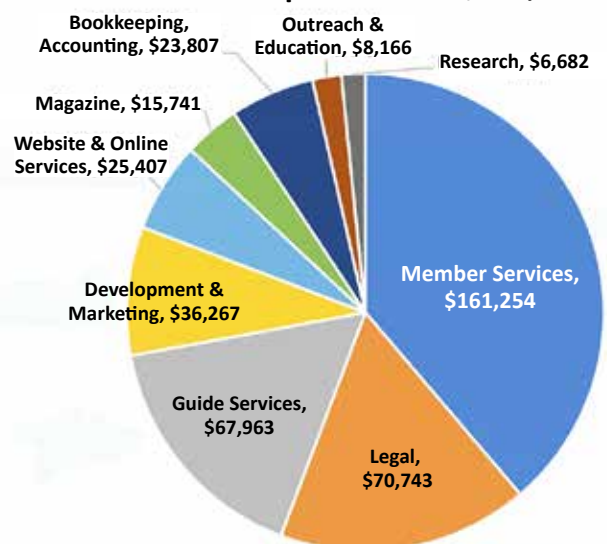
Our Outreach & Education Committee and Surrogate Consultant met the pandemic challenge by participating virtually in numerous conferences and events. This grows our ability to spread the FEN message to groups that might otherwise not find us.

Legal expenses were down a bit in 2020-21, but we expect a significant increase this year for Minnesota.

2020-21 Revenue = \$639,583



2020-21 Expenditures = \$416,030





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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.

– Some FEN Partners –

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



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Good Endings Book Club



Scripting Death

By Mara Buchbinder

Reviewed by Jim Van Buskirk

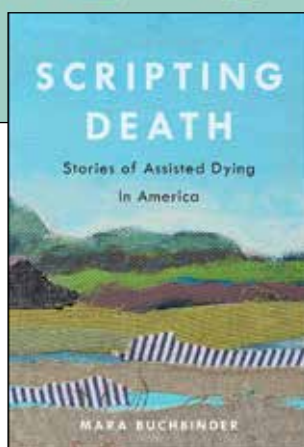
This book affords a fascinating exploration of the seemingly narrow focus on the development and implementation of right-to-die legislation and the surrounding social, ethical and medical issues.

Mara Buchbinder, who teaches at the University of North Carolina, posits that, “Until now, very little has been publicly known about how medical aid in dying (MAiD) laws affect ordinary citizens once they are put into practice.” She offers an in-depth account of how all MAiD stakeholders navigate legalized aid in dying as a new medical frontier.

Emphasizing the politics of language, the author tries to clarify terminologies employed by proponents and opponents in the U.S. and abroad. She notes that U.S. proponents deliberately changed terminology from “physician-assisted death” to “aid in dying or (MAiD) to decenter the role of physicians.” To complicate matters, in other countries, *aid in dying* is a term that may include physician-administered drugs (known as euthanasia) and patient-administered medication (called assisted suicide). In America, only the latter is permitted.

Although she “remains quite ambivalent about the practice,” Buchbinder uses “medical aid in dying” throughout the book. She also uses “aspirational death to signal the aesthetic, affective, and ethical preferences that inform orientations to dying as a matter of personal choice and careful choreography.”

“A fundamental proposition of this book is that scripting death through (MAiD) fundamentally alters dying by permitting people to control its trajectory ...



yet it also permits people to control the cultural and personal meanings of death,” she writes.

Buchbinder interviewed 144 physicians, terminally ill people, caregivers, activists, legislators, and other policy stakeholders, and she includes a robust appendix, end notes, bibliography, and index.

It nevertheless is remarkably readable, and it is an important contribution to the ever-evolving conversation around this controversial topic.

The Lady's Handbook ...

By Sara Ramey

Reviewed by Judith Hinds

This broadly researched memoir does not directly touch on right-to-die issues, but closely examines quality of life in the modern medical context.

It chronicles the misery and frustration of those (mostly women) with modern chronic illnesses who are overlooked, disrespected, and mistreated by many MDs. Ramey's story sheds light on the sad tales FEN volunteers often hear from folks who call seeking information about the Exit Guide Program.

Chronic pain or fatigue, chronic Lyme disease, multiple allergies, endocrine dysregulation, autoimmune conditions, recurring infections, “brain fog” – they're all here, along with the latest theories of why they've increased 300 percent in the past 30-plus years.

Recounting the intimate details of her 17-year journey, Ramey discusses what functional medicine and alternative medicine have to offer, as well as the importance of making lifestyle changes and getting the right tests on the road to a diagnosis.

She makes a case for the mystery illnesses as “the climate change of the human body,” caused and/or aggravated by environmental stressors of all kinds: chemicals, sugar, mold, sleep issues, food allergies, infections, trauma, noise, and other unrelenting pressures of modern life.

As much a manifesto as a memoir of chronic illness, debilitating pain, and medical misogyny, the handbook is written in a conversational style that keeps one reading against all odds. Ramey (aka musician Wolf Larsen) hails from a family of physicians, so



her justified rage at her mistreatment is tempered with inbred respect for the hard-won MD degree.

Trigger warning: Ramey graphically describes the bungling and outright abuse she experienced at the hands of certain urologists and gynecologists. Readers likely to be triggered by this content should proceed with caution.

Because FEN believes in choices for both dying and living, and in the power of compassionate listening, we can appreciate Ramey's call for more funding, research, and understanding of contemporary chronic diseases. As she makes clear, the worst part of suffering with a mystery illness is having your friends, family and doctors not believe you're really sick.

(Editor's note: The reviewer is a FEN coordinator and associate guide.)

The Next Room

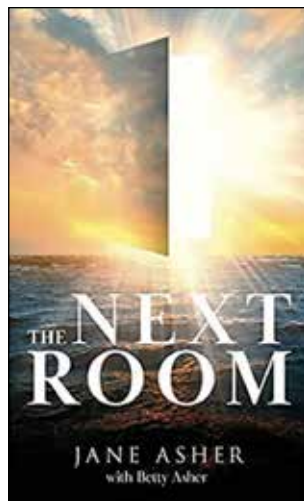
By Jane Asher

Synopsis by Judy McNutt

Who co-writes a life-changing book with her mother? Then we discover that although Jane's writing partner has "left the room," Mom has "leveled-up" and still has much to share, not only with her daughter, but also with all of us baffled by life or suffering a loss. Love "The Box" philosophy!

This book evolves from personal love and loss to expansive awakening.

(Editor's note: Jane Asher does The Next Room podcast and is a staunch friend of Final Exit Network.)

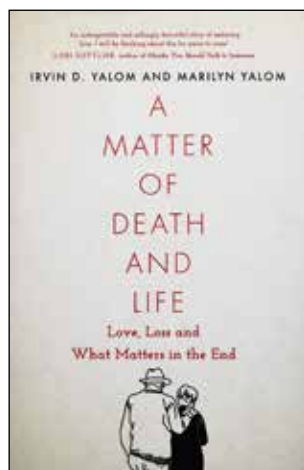


... Death & Life ...

By Irvin & Marilyn Yalom

Synopsis by Jim Van Buskirk

Renowned psychiatrist and author Irvin Yalom and esteemed feminist writer Marilyn Yalom were teenage sweethearts. In alternating chapters, they reflect on their 65 years together, their deep devotion to one another, their four children, their many grandchildren, their work,



and their friends. Always deep thinkers, Irvin and Marilyn describe the quotidian joys and challenges as old age and infirmity encroach.

When Marilyn is diagnosed with multiple myeloma and ultimately fails to respond to medications, she decides to use California's physician-attended death-with-dignity option.

From their acknowledged position of privilege, this inspiring couple investigates universal issues of intimacy, love, and grief, leaving a powerful and poignant portrait of lives well lived.

MAiD, Canadian style

Canada released its [2020 annual report on Medical Aid in Dying](#) this summer. It revealed a robust increase in Canadians taking advantage of the law.

- Of 9,375 MAiD requests, 7,595 were approved. That's a 34% increase over 2019, and 2019 was a 26% increase over 2018.

- Rejected requests dropped from 8% to 6%.

- MAiD comprises about 2% of all Canadian deaths, but that rises to 4% in British Columbia and 3% in Quebec.

- MAiD usage is nine times higher in British Columbia than in the neighboring state of Washington.

- Canadian eligibility is wider, not limited to terminal illness with a six-month prognosis. Since Bill C-7 was enacted in March, death need not be "reasonably foreseeable."

- Virtually all Canadian MAiD is administered by a clinician, while every U.S. MAiD patient must self-administer – euthanasia is strictly illegal here.

FEN extends outreach to aging-in-place communities

Final Exit Network was a major participant in the Oct. 5-7 online national conference for Village to Village (VtV), a network of 292 communities that promote "aging in place" – living at home or in a residence of one's choosing.

FEN hosted a virtual booth with two videos and downloadable materials, and nearly half the event's almost-600 attendees visited the booth.

FEN had two requests for speakers bureau presentations, got almost 100 leads for follow-up, and will stay connected with VtV communities.

In
the
swim



... until you're killed in the name of mercy

Euthanasia ignorance fuels confusion, misconceptions

By Jay Niver, FEN Editor

Linguistic errors do not threaten the right-to-die cause. They don't encourage violent suicides that could be averted with more Medical Aid in Dying (MAiD); no peaceful exit depends upon what some uninformed official says about killing a nuisance reptile.

That said, in the right-to-die movement, most of us are keenly aware of the difference between euthanasia and MAiD. Unfortunately, some are not. There's a pervasive misconception about terminology, fueled by public and media ignorance.

MAiD, in every legal jurisdiction, requires that people who have qualified for terminal drugs are able to take the meds without assistance. Euthanasia, on the other hand, is the active killing "of hopelessly sick or injured individuals ... in a relatively painless way for reasons of mercy" (Merriam-Webster). According to Oxford, it is "the painless killing of a patient suffering from an incurable and painful disease or in an irreversible coma."

Other dictionaries include non-human animals as eligible, and about 2,500 innocent dogs and cats that are "put down" daily suffer mainly from a lack of loving homes – they are not physically sick, injured, or in pain. *Are they being euthanized?*

Wikipedia (unlike others) has a separate definition for "animal euthanasia," which conveniently accounts

for the slaughter of healthy shelter animals. It says, "Reasons for euthanasia include incurable (and especially painful) conditions or diseases, *lack of resources to continue supporting the animal*, or laboratory test procedures" [italics added] that send 40,000 lab animals to death every year.

Beloved pets are "put to sleep" by caring owners and veterinarians. That is euthanasia. (We still hear, "Let me die like a dog" in RTD parlance.)

U.S. media, and our Canadian friends, report almost daily on the killing of healthy, innocent animals that have done nothing to deserve a premature death.

In almost every case when a bear wanders into a backyard, when a gator bites someone swimming in his water, when a big cat chases someone hiking in his habitat, when lynx kittens or bear cubs lose their mothers, when coyotes roam through an urban park – the animals are allegedly "euthanized," if we believe what we read or hear in the news.

There is no linguistic case to apply "euthanasia" to the killing of homeless pets or nuisance animals. When you kill a healthy animal, just say, "We killed it."

Once we start using "euthanize" correctly, and admonish those who abuse it, maybe we can bring a clearer, more-meaningful public dialogue to the RTD topics of euthanasia and Medical Aid in Dying.



FEN is called a lot of things - this one is positively good

By Jay Niver, FEN Editor

Ann Mandelstamm was never a pariah. The longtime FEN coordinator for Exit Guide Services was not unlikeable and was hardly offensive. She'd been a high school English teacher for 35 years, had plenty of friends, was well-respected, and raised three great kids.

Still, she says, something was missing: "I felt pretty comfortable, but I never quite fit in anywhere I was in life."

That changed after she retired, when her children were grown and successful on their own.

"I've always needed meaning and purpose in life," Ann says. "When I was teaching and raising children, I had meaning and purpose out the wazoo. But once I retired, I was lost. I wasn't going to have a whole new career, and I certainly wasn't going to have any more babies."

Final Exit Network became her baby, and she confessed as much at a FEN Chicago meeting. As Ann recalls, volunteers were informally sharing what they thought were the best (and worst) things

'I'm not ending my days in a wheelchair in a hospital basement waiting for some more chemo.'

about the organization. When it came to her, she blurted it out: "The best thing is, I found my tribe!"

Says Ann, "People laugh at me because I say this, but it's true: Here's my tribe. I found it! I love it. I love the people in Final Exit, even the ones I tangle with once in a while."

Ann's affinity for the right to die began when she was a young adult. She explains: "I noticed my parents' friends, in their 60s and 70s, and many of them had cancer. They would go through these terrible things, surgeries, chemo, radiation ... and some of them did recover. But then, if they lived into their 80s and 90s, many of them developed dementia.

"So after all that suffering and medical care, they ended up mostly in nursing homes, not knowing where they were and what they were doing. These were really fine, well-educated, sharp people, and it ended up so badly.

ANN
FOUNDED
HER
TRIBE



Ann Mandelstamm

"It made me feel like, 'There's something wrong with this.'"

That's not for Ann. "If I ever get some kind of fatal illness, I'm not ending my days in a wheelchair in a hospital basement waiting for some more chemo," she says.

Ann, 82, is nowhere near that point, but admits, "I'm getting older, and my memory is not as great. I'm worried about maybe forgetting something important, because there are so many, many pieces about being a coordinator, and you can't let any of them drop."

Ann has coordinated over 100 clients who were approved. More importantly, she says, "There are thousands of people I've talked to" in the last seven years. Many never applied for exit services, but recruiting is not what FEN coordinators are about.

"It's so valuable to sit and talk with them, to educate and answer their questions about VSED or anything else," Ann explains. "This has been a godsend for me. I feel so lucky because FEN just gave me so much in my life."

Others would say the same thing about Ann Mandelstamm.



“The room was full of kids, grandkids, great-grandkids – and LOVE.”

A premature party was right on time

By Sharon Parks

I am an RN who worked in hospice for several years. I quickly became an advocate of the right to die.

My mom wanted to live to see her 80th birthday. About 10 days before she passed, we (the family) realized she would not make it. While she was in the hospital, we had angels for a doctor and hospital staff.

We celebrated her birthday one week prior to the actual date. She planned it and even directed how she was to be dressed and nails painted (she never wore nail polish). The attending physician even sent flowers for her birthday (he had not met her prior).

She asked for KFC and trimmings. She barely ate, but that wasn't the objective. The room was full of kids, grandkids, great-grandkids – and LOVE.

That night EVERYONE wanted to stay with her. The staff was so understanding, they let as many of us remain as could squeeze in the room. (Once we found a spot to doze, we didn't dare move, afraid someone would take it!)

Her doctor spoke long and privately with Mom to make sure DNR was her wish. After that, the staff only came in when we asked them to. The doctor was not on call that weekend, but he called me to make sure our/her needs were being met and wishes respected.

Finally, everyone did go home except for my sister and me. We sat on each side of the bed and held her hands. As Mom drifted away, I spoke my sister's name and our eyes met, understanding that she was gone.

It was absolutely the best “death” we could have imagined, outside of her dying quietly in her sleep.

This was over 20 years ago, but it still brings the utmost joy to our family.

Unfortunately, my father wasn't so fortunate.

He developed sepsis in a hip replacement and suffered for three months in the hospital. It wasn't until near the end that family realized he would not survive. I was his Healthcare Power of Attorney and lived 1000 miles away, or (I hope) I would have been more proactive. He passed away a week before his 82nd birthday – *alone*.

Another family experience: My husband's father had Alzheimer's and “died” about three years before he stopped breathing. My husband is convinced he will also develop dementia and has made clear to me his wish that he doesn't want to go the same way, for my sake and for his dignity.

Thankfully, my daughter (Power of Attorney) works in a hospital and shares my views. If it is possible, she will make sure my wishes (and my husband's) are followed.

I hope FEN is available. Even more, I hope that MAiD will be readily accessible, so his death doesn't have to be clandestine.

Thank you for the work you do and for giving me this opportunity to share



The author's mother enjoyed a KFC dinner for her last birthday party, surrounded by her loving family.

(Editor's note: The author lives in North Carolina where [Dying Right NC](#) has succeeded in getting bipartisan MAiD bills filed for the past two legislative sessions, 2019 and 2021. In the state's conservative-controlled legislature, they have gone nowhere, though North Carolina is one of the few states where there is no law against assisting a suicide.)



Clinician group focuses on all things MAiD – except advocacy

By Lonny Shavelson, MD

The American Clinicians Academy on Medical Aid in Dying is the second of two firsts.

1) On Feb. 14 and 15, 2021 (just before the pandemic closed everything down), more than 300 clinicians from around the country attended a conference at U.C. Berkeley focused exclusively on caring for patients considering Medical Aid in Dying (MAiD).

We talked about everything from the pharmacology of aid in dying to the role of hospice, to ethnic and spiritual considerations in aiding death, and much more.

2) To continue work past that milestone, we announced the formation of the first Academy for Aid-in-Dying Clinicians. And, in the ensuing year and half (we're still just a baby), we've made inroads on all of our goals.



Dr. Lonny Shavelson

The Academy is quite distinct from other aid-in-dying organizations: We don't advocate for MAiD; we don't lobby for new laws or approach legislators. We even studiously avoid the term "death with dignity" as a euphemism, since there are many routes to a dignified death. MAiD

clinicians have no monopoly on that.

What we do is straightforward: We learn, investigate, establish, and teach the clinical aspects of Medical Aid in Dying, so that terminally ill patients who are considering or acting on this option receive the best information and medical care possible.

The Academy provides:

- A clinician hotline, with experienced doctors to consult with newer clinicians as they care for aid-in-dying patients;
- Free continuing education online sessions for doctors, nurses, social workers, chaplains, and hospice frontline staff;

- A patient-to-doctor referral system to connect patients considering aid in dying with supportive and experienced physicians. We've had more than 250 requests, and have successfully placed every qualified patient with a participating doctor;

- A listserv of more than 500 participating clinicians to discuss aid-in-dying care;

There are many routes to a dignified death. MAiD clinicians have no monopoly on that.

- Aid-in-dying pharmacology investigations, innovations, and updates that have markedly improved the efficacy, reliability, and safety of medications;

- Position papers on everything from TeleHealth to pacemakers to rectal MAiD medications for patients who can no longer safely swallow the drugs;

- A first-ever Aid in Dying Ethics Consultation Service, not to debate the ethics of MAiD, but to provide ethical guidelines for clinicians facing dilemmas in aid-in-dying patient care;

- Patient and family videos and written materials to help prepare for and complete their final day;

- A red-flag checklist for potentially complicated and/or prolonged deaths – so clinicians can know beforehand if complications might arise;

- Teaching and consulting with clinicians in states like New Mexico, where MAiD is newly legal;

- Improving bedside attendance on the aid-in-dying day by coordinating with states that are newly forming volunteer networks, and by an upcoming online training for end-of-life doulas.

The [American Clinicians Academy on Medical Aid in Dying](#) informs and educates clinicians, from patient-care discussions to evidence-based knowledge, from prognoses to pharmacology, from the role of hospice teams to evaluations of decision-making capacity, and what "self-administration" means in the real world.

We are the first formal organization to research, establish, and inform about the best clinical practices for Medical Aid in Dying.



Hold a dying friend's hand –

TAKE A RIDE IN A SQUAD CAR

By Laura Kenig, FEN Member

I remember getting in the back of that squad car with some fear, thinking, “Uh oh, should I be getting a lawyer?”

My friend Judy had asked me to be by her side when she chose her final exit. I said I would. She spent the next six months preparing and informing me of her plans. We discussed them at length and planned how I could be with her without assisting in her death.

She had the book, *Final Exit*, and used that as her guide.

Judy had been suffering from Chronic Fatigue Syndrome following the death of her son, 40-plus years old; she also was recovering from thyroid cancer and a divorce from the love of her life. She tried to heal with every method of treatment available and to be able to sustain her lifestyle, with no success. She could no longer work due to the debilitating effects of Chronic Fatigue. She was going to lose her house. She was estranged from much of her family.

I went to every length I could to encourage her, suggesting alternative methods and diet, and even



Judy (l) and friend Laura enjoy a toast.

suggested she go to a Brazilian healer. I also told her that if, at any point, she had doubts about her choice to end her life, I could not support her – she was clear and never faltered in her decision.

Judy chose to use helium as her means of departure. She purchased everything she would need and set it up on her bed, and she had a couple of trial runs without turning on the gas. She wrote letters to all her friends and loved ones and had met with her lawyer. Judy was ready.

She died peacefully in her bed as planned, with me holding her hand. She went unconscious instantly. I made the mistake of not educating myself about the dying process, and I panicked when she lost consciousness,



Judy

***We were separated at the police station.
I sat in a small room and was questioned
intermittently for the next four hours.***

because she still had a pulse and was exhaling loudly for about 10 minutes.

I took a couple of runs to the bathroom as my nerves were frayed. I feared she could be brain dead and imagined the worst-case scenario of her being a vegetable in a hospital bed. Eventually her organs shut down and all was quiet.

I then called a friend who lived nearby, and she came over immediately. I left a message for Judy's ex-husband, and he arrived a short time later. She had left instructions to call him after she died and that he was to call the coroner, which he did. The person at the coroner's office asked how he knew she was dead (it was obvious), and said the former husband was not authorized to determine death; we needed to call 911. This was really frustrating!

So we phoned 911 and were bombarded by first responders. As I sat in the living room, the police and firemen showed up, and I directed them to the bedroom, informing them that she had a DNR. (I feared that they might attempt to resuscitate her.)

I wanted to be up front about being with Judy and told the police I had been by her side when she died.

The three of us (friend, ex-husband and myself)

were asked if we would be willing to go down to the police station for questioning, and we all agreed. I did not have anything to hide and wanted to cooperate to alleviate any concerns. I knew I had taken every precaution to protect myself.

We were separated at the police station. I sat in a small room and was questioned intermittently for the next four hours. I was asked if they could take my phone, which they did. It was returned to me a few hours later. I reached my limit and was exhausted and told the investigator that I wanted to go home, and he gave me a ride.

Unbeknownst to me, my friend and Judy's ex had been released a couple of hours earlier.

I called my neighbor and was debriefing with her when, about an hour later, the investigator showed up at my house around midnight to inform me that I did not have anything to worry about – everything checked out – and I was cleared.

What I learned from my choice to support Judy's decision is that I subjected myself to potential prosecution and accusations from family members and friends.

It is with great relief that I can say that Judy's ex-husband was incredibly grateful to me. He understood her suffering and thanked me for being by her side. I am fortunate that others in her family did not decide to make accusations, and that the police did not see a need take this further.

With the help of the book, *Final Exit*, I did everything correctly to protect myself. I was able to give my friend her dying wish: not to be alone at her final exit.

I miss Judy dearly, but I know she isn't suffering and that what she did was the right decision for her. It's too bad that we have to be so careful simply to be with someone who makes this decision to exit peacefully on their own terms. It makes what could be a loving, family affair a secret, clandestine event! *Such a shame.*

Fortunately, there are FEN Exit Guides to help, so you don't have to do it alone, as Judy and I did!



Disabled are excluded from MAiD option

By Jay Niver, FEN Editor

Some strident disability-rights groups – most notably, Not Dead Yet – have long contended that Medical Aid in Dying laws allow disabled people to be forced into an early death. Such right-to-die measures discriminate against them by inappropriately putting them at risk, they allege.

Now some disabled persons agree that such laws discriminate – *for an opposite reason*. And they are joined as plaintiffs by some high-profile right-to-die advocates including doctors and attorneys.

Put simply, they assert:

Because every U.S. MAiD law requires patients to administer life-ending drugs themselves (with no assistance), disabled persons who are unable to do so cannot avail themselves of the option to die on their own terms. The law inappropriately excludes them – *and that discriminates*.

What happens in some heart-wrenching cases is that a dying patient “leaves good time on the table,” taking his or her life before they want to. If they wait too long, their MAiD option is gone.

A civil-rights [class action filed this summer](#) in federal court specifically targets California’s End of Life Options Act (EOLOA). According to the plaintiffs, it seeks “to rectify the exclusion of physically disabled individuals” and secure “reasonable accommodation to ensure physically disabled Californians are afforded equal benefit of the EOLOA.”

The plaintiffs are represented by attorney Kathryn Tucker. She was executive director of the Disability Rights Legal Center, which fights tooth and nail for disabled people. Her record reveals a fierce advocate for them – not someone who would attack them or try to limit their freedom, especially at their end of life.

Plaintiffs are also represented by another leading



disability-rights litigator, Cat Cabalo, and civil-rights lawyer Adam Wolf.

Plaintiff Sandy Morris has advanced ALS, causing progressive loss of muscle control. A mother of three, she is now entirely dependent on caregivers and will soon lack the hand strength and coordination to ingest MAiD medication without assistance.

Morris is being forced by the EOLOA to decide



Not Dead Yet protestors have opposed RTD laws for decades, claiming it puts disabled people at risk. After 60 combined years of U.S. MAiD, there is no documented case of a disabled person being put to death against their wish.

between ending her life sooner than she wants or suffering the slow, painful death she wants to avoid..

Dr. Lonny Shavelson (see story on page 11) is one of her treating physicians. He would like to assist her if she needs help to ingest the medications, but knows he is barred from doing so.

“I have seen the assistance prohibition adversely impact dozens of patients,” he said, “forcing them to act too soon, or wait and endure the prolonged sort of death they hoped to avoid.”



THE BACK PAGE

A COMPENDIUM OF RIGHT-TO-DIE WORLD NEWS

United States

• **California** got a new law in October that removed major hurdles to MAiD access for the nearly one out of every eight U.S. residents who live in the Golden State.

California's End of Life Option Act required patients to wait 15 days between making two oral requests for lethal medication. The new law reduces that waiting period to 48 hours and extends the law's sunset date to Jan. 1, 2031, giving the legislature an additional five years to make MAiD a permanent option.

Also, hospitals and hospices will now have to post their medical aid-in-dying policies on their websites, increasing transparency for terminally ill patients.

• **Massachusetts** residents are waiting to be granted the same EOL rights as people in California.

The End of Life Options Act was filed this fall, and a hearing was held in October. At press time it was unknown if the measure would move out of committee.

Nearly a decade ago, voters narrowly rejected a ballot option to legalize MAiD.

Versions of legislative bills have been filed for years. In 2020, the Public Health Committee redrafted and brought bills to the Health Care Financing Committee, which did not take action to advance the measure.

The current proposed legislation has more than 80 co-sponsors.

England

Britain's biggest doctors' union dropped its 15-year opposition to assisted dying in September.

The British Medical Association, which represents some 150,000 members, held a landmark vote after a survey last year revealed the majority supported a change to the law.

More than 300 members of the BMA's representative body participated in the poll. A slim majority backed the change to adopt a neutral stance on the issue.

Slightly fewer than half of the BMA members who voted did so in favour of holding a neutral stance on assisted dying. Another 48 percent were against it and 3 percent abstained.

But, if assisted dying becomes legal, they said they would support medics' right to refuse prescribing lethal doses of medication if they object.

Scotland

A bill to change the law on assisted dying in Scotland was filed in September, part of a U.K.-wide push that coincided with publication of a major report that said 78 percent of U.K. residents support allowing doctors to assist in the deaths of terminally ill patients.

It parallels a bill introduced in the House of Lords, where backers cite a 2019 poll that showed 87 percent support among Scots.

The bill is backed by a cross-party group of 12 lawmakers who signed an open letter, stating: "The current law does not work and should be replaced."

Canada

A surge in demand has led Nova Scotia to pause MAiD referrals. Officials say it is a symptom of stress (including COVID-related) on the healthcare system.

The province put a 30-day hold on assisted-dying requests while it works through a "significant backlog."

Referrals in the province this year have already outstripped the total from all of 2020, when there were 373; as of September, there had been 395 referrals.

Canada's *Dying With Dignity* said the organization has been hearing of increased referrals for assistance across the country, spurred in part by changes to the law this year that made eligibility criteria easier to meet.

Colombia

Martha Sepúlveda, 51, was to be the first person in Colombia (a majority-Catholic country) without a terminal prognosis to die by legal euthanasia in October. But a surprise 11th-hour decision by health officials halted her bid.

Her procedure was canceled after a medical committee determined she no longer met required conditions, because her health apparently had improved.

Sepúlveda's law firm has vowed to fight the decision and points to a recent constitutional court decision that allows euthanasia for patients with intense physical or mental suffering from bodily injury or serious and incurable disease, even if the prognosis is not terminal within six months.

Sepúlveda was diagnosed with amyotrophic lateral sclerosis, known in the U.S. as Lou Gehrig's disease, in November 2018.



Nov. 17 Minn. hearing may be Zoom accessible

A federal court hearing set to take place in November in Final Exit Network's lawsuit against the authorities in Anoka County, MN, will be conducted via Zoom, which may enable FEN members, volunteers, and supporters to listen to the hearing live.

It is scheduled (as of press time) for 10 a.m. Central Time on Nov. 17 in the St. Paul courtroom of U.S. District Judge Nancy E. Brasel.

FEN had previously encouraged supporters to attend the hearing in person. Instead, Judge Brasel's office announced on Sept. 21 that the hearing would be conducted online via Zoom.

Only the attorneys will be able to join visually in the Zoom conference, as lawyers for the Anoka County prosecutor and sheriff will argue their Motion to Dismiss FEN's lawsuit. They argue that the FEN suit should be tossed out without a trial because it lacks merit.

FEN's lawsuit asserts that a Minnesota law prohibiting giving people information on how to cause their own peaceful and dignified death violates the First Amendment.

Anoka County authorities are being sued because they are actively threatening to charge FEN and two of its Exit Guides in connection with an incident that took place May 5 in Columbia Heights, a northern suburb of Minneapolis.

It has not been determined exactly what means of public access will be available. The hearing may be made accessible as part of a federal court pilot program in which audio of certain qualified hearings

will be streamed on YouTube at: <https://www.youtube.com/c/USCourtsMND>

Alternatively, beginning on about Nov. 10, a telephone number will be posted at the website of the U.S. District Court for the District of Minnesota (<https://www.mnd.uscourts.gov/media-information>) along with instructions to access the hearing by phone.

The Anoka County defendants argue basically that in light of the controlling legal authorities, the FEN lawsuit cannot succeed and must be preemptively dismissed. FEN argues that county authorities' argument is incorrect on the law.

If the Motion to Dismiss is granted, the lawsuit will be terminated. If the motion is denied, the lawsuit will go on to further proceedings.

When the Nov. 17 hearing is over, the judge might take months to enter a written ruling on the motion.

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

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.