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VOL 19 • No 3

SUMMER 2020

Alzheimer's: the torture of dementia

1st SADD participant faces multiple devastating losses

By Jay Niver, FEN Editor

She was strikingly beautiful. Still is, to her husband, “Ron.”

She was “a voracious reader and highly articulate,” he said. She was verbal – fluent, charming, and expressive.

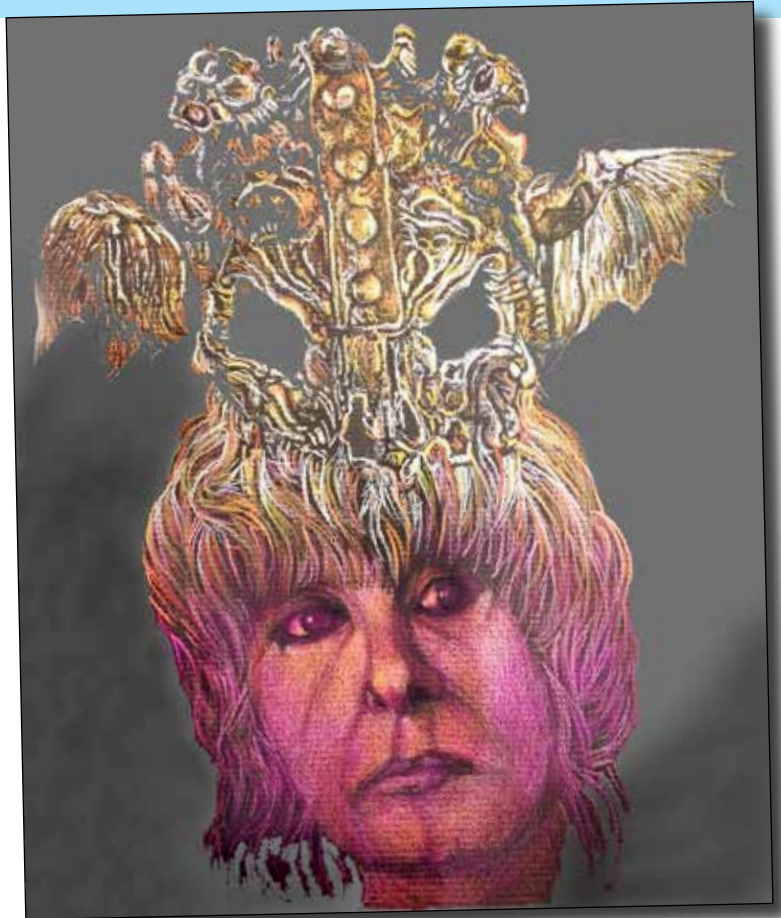
“Our courtship was spent talking about everything,” Ron said, “from Byzantine icons to feminist theory.”

She was one of a tiny cohort of women “who could cast bronze, weld, and work metal from rough finish to patinization,” he added.

They worked hand in hand, and heart in heart.

Now she has trouble finding words. Can't speak well. Can't read easily. Language is failing her.

“Michelle” has Alzheimer's. It took her



SELF-PORTRAIT – Michelle made this drawing to show what it feels like to have Alzheimer's. “She's not yet lost any of her right-brain acuity,” said her husband.

mother and her mother's sister. Michelle told Ron more than 20 years ago, “If that happens to me, I don't want to be here.”

That was long before any inkling that she, too, would be afflicted by crippling dementia. There was no Final Exit Network at the time.

Michelle and Ron are both artists, and they first crossed paths pursuing art in their

SADD continued on page 2

Renew your membership online: www.finalexitnetwork.org

respective media.

She had attended art school and worked for years as a freelance illustrator. She moved to the Northwest, where she met Ron and finished earning her degree.

Four or five years ago, when she first realized she had dementia, he recalls, “she researched ways end her life.” Drugs from Mexico, asphyxiation, helium suicide – she did her homework. Besides, as a sculptor who worked with metal, Michelle knew the science of inert gases.

She got a tank of nitrogen, a regulator, and a bag. Her set-up was ready four years ago.

Then Ron heard FEN President Brian Ruder one day on the radio. “Holy s---,” he thought. “These guys do this!”

In May, FEN launched a nationwide initiative intended to strengthen end-of-life safeguards through a new Special Advance Directive for Dementia Care (SADD). In conjunction with other Advance Directives, it could ensure that people who have signed it when competent will have it honored when they no longer are.

SADD’s special focus is to make sure that an individual’s directive not to be manually fed or hydrated is obeyed.

The SADD program is a resource for people who may lose competence but do not want to lose control of their death. When that time comes, FEN will litigate pro bono on behalf of those who have SADD protection if their dying wishes are not honored.

Michelle was the first to sign up. FEN legal counsel Robert Rivas mailed her the document in late May, and she filled it out. No notary was required in the state where she lives.

“Being first” is often newsworthy, and the couple

agreed to share their story. Ron was willing, he said, “if it’s something we can do to help promote self-determination in end-of-life matters.”

It wasn’t easy. Michelle answered some written questions and, as Ron transcribed her answers, “I was reminded once again of how much damage this insidious disease has done to her,” he said.

“She led a rich, full life with many friends ... Now she has become increasingly private. I suspect it’s her discomfort with words that just don’t come anymore.”

Ron continued: “I can’t imagine how she lives with the never-ending grind of her dementia. That she still smiles, loves. I know she enjoys her daily routine and finds pleasure in life’s small rewards. I believe that those are the things that keep her on this planet.”

(Editor’s note: SADD enrollment is still open by emailing: fenattorney@gmail.com)



In Michelle’s own words

○ *My biggest fear is not knowing my husband, not knowing to go the bathroom to take a leak or dump, not knowing how to wash myself and take care of things in the house and not remembering how to draw, color, and paint anything.*

○ *My first reaction was considering hanging or shooting myself.*

– When diagnosed

○ *I do not want to go through what my mother and aunt went through. If my mother and aunt had not had (Alzheimer’s), I would still want to kill myself.*

○ *The best thing was making art and helping Ron make his lovely sculpture.*

– Most rewarding part of life

○ *No regrets when I will be gone because my life will have become so bad.*

○ *The supplement will ensure that my wishes will be followed, and I believe that anyone who feels the same way that I do should have one.*

– Will SADD make a difference

○ *I feel very fortunate that I have arranged to go when I want to and not have to go through what is coming.*

– Message to everyone

Programs ‘Zoom’ ahead

COVID-19 has not silenced the FEN Speakers Bureau. Presentations take place via Zoom or other online platforms, *and attendance is up because no one has to travel!*

If your church, civic group, or other organization would enjoy a FEN presentation, email (finalexitnetworkcontact@gmail.com) or call us (866-654-9156), and we’ll hook you up.

FINAL EXIT NETWORK

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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.

Fiscal Year 2019-20

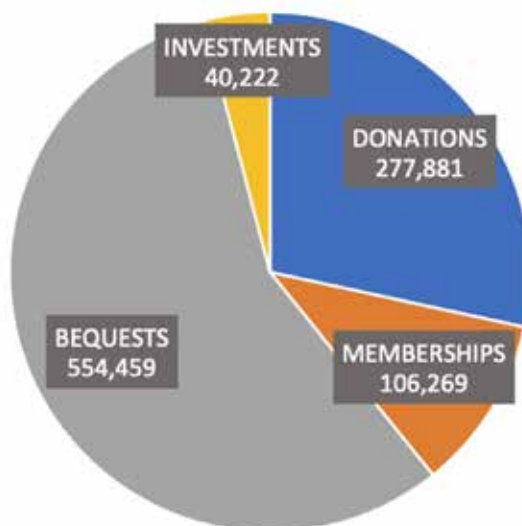
Financially it was a good year for FEN as we had income that exceeded expenses by almost \$400,000. This is explained in part by our being unable to travel since March due to the pandemic. Therefore, guides were not traveling and our meetings were held via Zoom, not in person.

Bequests totaled more than donations and membership dues combined and continue to be a very important source of revenue for us.

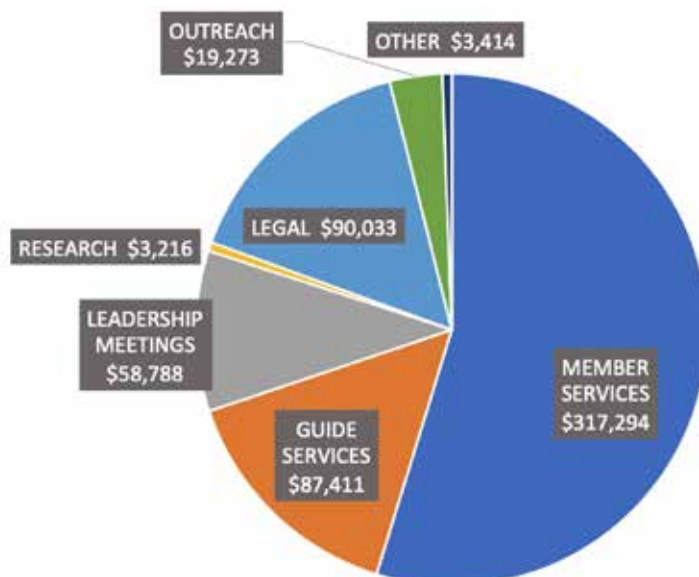
So, we ask you to please remember us in your will. And because we did not have any court cases, our legal expenses were moderate.

— Treasurer Judy Snyderman

INCOME • \$978,831



EXPENSES • \$579,429



*By Richard MacDonald, MD
FEN Advisory Board*



Neta (NEE-tuh) was a Florida resident I met during my speaking tour there. She requested some personal time before a meeting near her home as she wished to learn what Final Exit Network offered to members and supporters.

For years, Neta belonged to The Hemlock Society and learned it no longer had a support program for those wishing to plan their end-of-life choice. That led her to join FEN, and Neta revealed by email that she would be changing her targeted support to us.

Two years later, I was told that Neta applied for Exit Guide services. After being approved, Jim Chastain, a Guide who lived in Florida was assigned, and Neta asked that I be on her Guide team. I assured her I would be honored, but hoped it would be some time before she felt the time was right. Meanwhile, she said she found such peace of mind to know FEN would support her when she chose.

Neta embarked on a crusade to publicly try to improve social issues. She wrote four books, part memoir and part issue-oriented, like the right of patients to control how and when they die.

One of her books was a memoir of a round-the-world cruise she took, which she said was in tribute to her husband, John, with whom she enjoyed a similar cruise many years earlier. For another book, she asked me and others to contribute about dying and how one should have the right to control that important part of life. We often had email conversations about it.

Neta would conclude all our communications with "Peace and Love."

Fast forward to 2020. Neta was working on another book and apparently still able to enjoy her mostly home-bound activities. On the last day of January, she was admitted to the hospital in severe

due to a compression fracture of a vertebra, secondary to her long history of osteoporosis. She immediately stated, "This is it!"

Calling from her hospital bed, Neta said physicians warned her for years that multiple bony compressions might occur. The pain was so intense, she didn't wish to risk any more, and she feared a nursing home would be required to care for her. She asked to set a time for her long-standing plan to exit.

She did, however, accept the advice of her orthopedic doctor, who suggested the pain could be controlled by an injection of stem cells into her vertebra. This procedure entailed a minimally invasive approach with reportedly excellent results.

A day after the treatment, Neta told me she was much more comfortable and would be discharged soon.

As soon as Neta returned home, she started planning an exit date. She had two good friends who would be with her when she died, and she had all the needed apparatus to accomplish that.

Unfortunately, her Guide died before Neta arranged her exit. She had contacted FEN President and Senior Guide Brian Ruder, with whom she had connected after he called to acknowledge her annual FEN donation. He agreed to be on her Guide team when she wished to proceed.

With Neta, Brian and I agreed to a date in the last week of February, and Neta organized her friends for then. Brian and I arranged our

travel plans so we could arrive about the same time, and

we booked hotel rooms.

Late in the afternoon, while I packed for my flight east, Brian called to say that Neta had again been admitted to the hospital. Due to the spinal injury, complete bed rest had been ordered to avoid other

COVID continued on next page

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VSED bests COVID for Neta

vertebral compressions.

Her usual activities before the fracture included being freely up and around, and having a personal trainer provide her with supervised exercises two or three times weekly. Being static in bed created another problem: Her lower legs swelled and caused increasing pain.

A doctor who made home visits prescribed pain medication and antibiotics. When symptoms became more severe, Neta was hospitalized for intravenous antibiotics and pain relief. Her panicked call to Brian stalled our travel plans.

I received daily calls from Neta; one of her private nurses described continuation of her leg symptoms and sent photographs. Pain medication was helping

On March 11, state and federal leaders realized that COVID-19 had become a global pandemic ...

some, but Neta became more insistent that she wished to be at home for her exit. She asked Brian and me to be with her soon after she returned home.

A consulting vascular specialist visited Neta in the hospital. He discontinued the antibiotic infusions and ordered compression stockings. In early March, Neta finally returned home.

As this cavalcade of the unexpected unfolded, another was added. On March 11, state and federal leaders realized that COVID-19 had become a pandemic as predicted by the World Health Organization. In my home state, California, the governor ordered all residents to isolate at home, essentially shutting everything down. Airlines were reducing flights. East Coast states soon had increasing numbers of virus-stricken patients, and hospitals reported overwhelmed Emergency Rooms and Intensive Care Units.

Neta resumed plans to proceed with her exit. She felt it could be weeks before she had the strength to act, and a date was set for late March. Then another hurdle arose: Neta's condo complex of mostly senior residents was at too much risk to permit visitors. So much for seeing her, let alone attending her exit.

At this point, Neta and I talked daily, and she somehow made great efforts still to proceed, without any seemingly possible road ahead. It was then that we discussed if she would consider VSED – voluntarily stopping eating and drinking – and ask for home

That afternoon, as usual, she ended the call as she ended emails for years: 'Peace and Love.'

hospice care.

With no hope of Brian and me traveling to her, Neta decided on VSED at the end of March. After two days, hospice accepted her for care at home.

I called Neta daily; occasionally, a nurse would answer to say she was resting but would call back. Neta was able to obtain morphine for pain, if she complained that lesser medication didn't help. Thus, she had some peaceful sleep, and with five days of fasting, her voice became very weak.

Still, in early April Neta was more able to speak, and I asked her about her intake of fluids. She said one of the private nurses gave her sweetened tea in small quantity, plus sips of water. Neta put the nurse on the phone, and she told me that she understood what Neta wanted – but her agency's supervisor did not approve.

When talking with Neta, I explained again that even small amounts of liquid could delay her death.

By April 9, Neta again sounded extremely weak. She said she was having little pain and sleeping a lot. Once more, I told her how disappointed Brian and I were at not being able to be with her. Neta said how much she wished that could have been possible, and she appreciated that we tried.

That afternoon, as usual, she ended the call as she ended emails for years: "Peace and Love." It was the last time we talked; my daily calls went unanswered.

I learned later that fluids were still being given. Neta's closest friend alerted the estate administrator, who intervened with a threat of legal action to finally get Neta's dying wish fulfilled.

Health crises and a pandemic thwarted her end-of-life plans, but not Neta's spirit and determination. Months earlier, anticipating death, she penned the following words excerpted from a message to her friends and family to be delivered after her passing:

To All My Angels

I am homebound now

On the greatest journey of them all ...

Earth time must not confine me

As I must answer the call of eternal time ...

Editor's note: Neta's real name was used with her permission, and she felt comfortable sharing her story.



'FEN's 15 FAVORITES'

THE BACKSTORY IS NO JOKE

By Jim Van Buskirk, FEN Volunteer

Old librarians never die, they just ... stop circulating, become overdue, check out, lose their references, close the book, get shelved in the basement (or get renewed) ... *Ba-da-bump!*

Having worked for years as a public librarian, I've heard 'em all. My background providing reference service and developing collections is likely why I was asked to work up a list of selected resources to help people initiate discussions about self-deliverance.

Now on our website, "[FEN's Fifteen Conversation-Starting Favorites](#)" includes articles, books, and documentary and narrative films. The offerings lead off with titles encouraging a general conversation, and then become more specifically focused on the issues of rational self-deliverance at the end of life, couples exiting together, VSED, dementia, and neurodegenerative disease.

We encourage everyone to start these discussions before anyone ever thinks this option might become necessary, so that if and when it does, the groundwork has been laid.

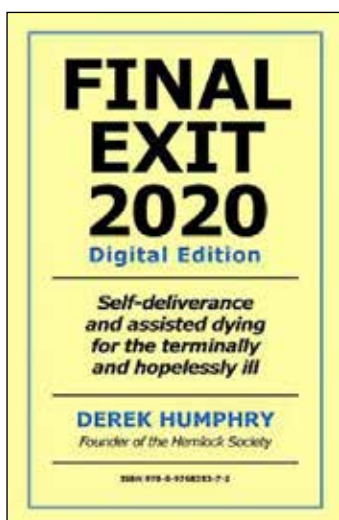
These are usually not easy conversations to

Derek Humphry's new ebook, *Final Exit 2020*, is getting response throughout the world. Orders for the download have come from Moscow, Zagreb, Oslo, Tokyo, Sidney, Paris, and London.

Most all of the orders are from North American people who want the updated version of the original

1991 *New York Times* bestseller. Profits from the ebook go to ERGO and Final Exit Network.

Visit the ERGO Bookstore at this secure site: <http://www.finalexit.org/ergo-store/>



Jim Van Buskirk

introduce, and convincing family or friends is not likely to occur overnight. It often requires repeated talks over time, but it is worth it.

It is worth it for the value of our relationships. It is worth it because each generation must teach the next, not only options for building a life, but also

options for leaving it.

In some way, my work began five years ago. When co-hosting a monthly Death Café, I noticed that participants frequently mentioned resources they'd found helpful. I couldn't refrain from making lists, which quickly became a bibliography.

Every time I heard about a new book, film or website related to death and dying, I tracked it down and added it to my ever-expanding bibliography, augmented with a sentence or two about the author's perspective, qualifications, and any other distinguishing characteristics.

When I became involved with Final Exit Network, I learned about even more resources. I shared the fruits of my labor, soliciting additional recommendations.

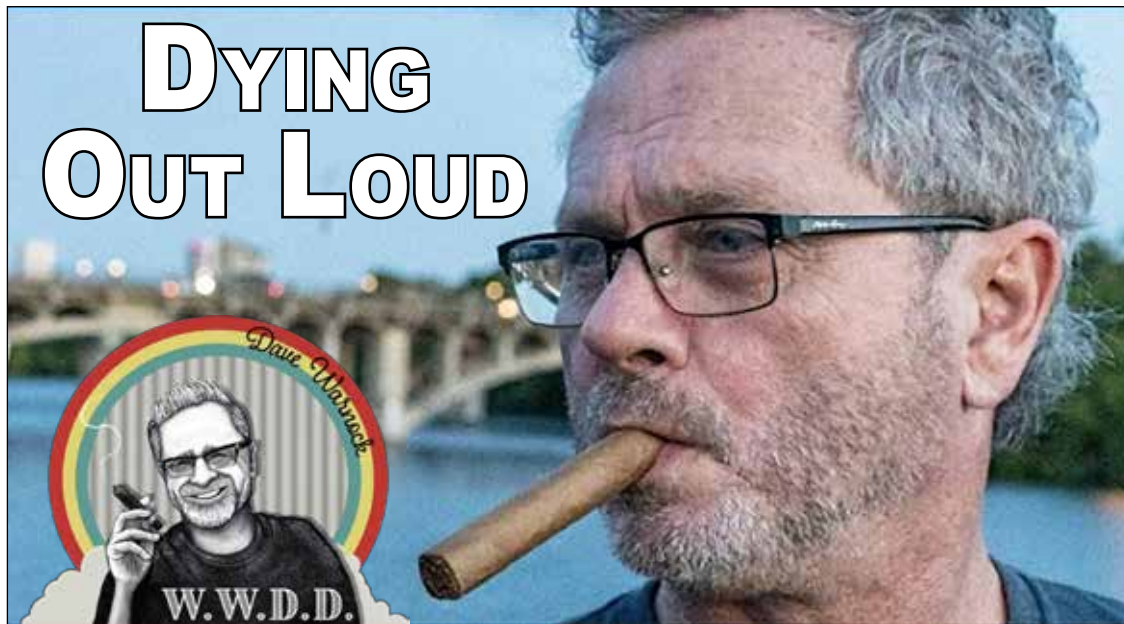
Updated sporadically, it now weighs in at 24 pages, containing nearly 300 entries.

I embarked on the arduous process of whittling the unwieldy list down to something more manageable, focusing specifically on the controversial topic of taking control of one's own death, as this was a resource to facilitate conversations.

Who doesn't like a little alliteration? So, when I facetiously called it *FEN's 15 Favorites*, the name (and number) stuck.

Back and forth, forth and back, phone calls and reformatted drafts, polling FEN colleagues until we had developed what we hope will be a valuable resource to help people start what might feel like a difficult or dangerous – but very important – discussion with friends, families, or physicians.





By Jay Niver, FEN Editor

Dave Warnock brings special meaning to the term “irreverent.” Not just because he’s a vociferous advocate for what he calls “Dying Out Loud” (talking impudently about death), but because he spent almost 40 years in the most “reverent” way possible.

Warnock was a conservative evangelical pastor and church leader. He preached the gospel. Now he preaches ... *well, it’s nothing you’ll hear from a pulpit.*

To hear him say it, Christians are taught to seek eternal life and commit their temporary earthly lives to getting there. Now he’s convinced there’s no eternity, so he concentrates on the here and now.

“I’m focused on living, not dying,” he said in June. “I’m trying to suck the marrow out of the bones of life. I’m living as long as I can as well as I can,” he said in a podcast last month.

Warnock gradually went from “believer” to “agnostic” to “atheist” – and he said the price was horrific: “I lost almost my entire community of friends, my wife of 37 years, and a relationship with two of my three children, which also deprives me of being a part of my six grandchildren’s lives.”

Seventeen months ago, he learned that he would be deprived of something maybe more precious.

“On Feb. 26, 2019, I received the devastating diagnosis of ALS (Lou Gehrig’s disease),” his website explains. He left the specialist’s office with “no follow-up plan ... no counselor referral ... just to go home and die in 3-5 years.”

ALS has a way of making folks ponder their mortality. Until Warnock got his bombshell news,

“I didn’t think about the right to die or death with dignity. It was a non-issue,” he said. “Then it became front and center.”

A friend of Dave’s referred him to FEN, and he met Executive Director Mary Ewert in Madison, WI. “It (FEN) was a no-brainer for me,” he said. “I saw no reason to make people suffer needlessly.”

“I’m focused on living, not dying ... I’m living as long as I can as well as I can.”

Dave’s partner, Bevin (not offended by his atheist worldview), was initially upset when he mentioned FEN. “I thought he was ‘giving up’ on life,” she said. She changed her mind when she realized he was *reclaiming* his life instead.

Bevin spends hours in online ALS chatrooms. The mentality, she said, is that “We’re going to beat this, there are new trials; people are really determined. But caregivers are overwhelmed.

“I ask them, ‘What if it doesn’t work and you don’t want to go to the end?’ I just hear crickets.”

Warnock doesn’t fear death but embraces life, so much that he launched the [“Dying Out Loud Tour”](#) for he and Bevin to travel and spread the new gospel around the country (and beyond). Dave was booked though July, then COVID-19 wrecked everything.

That, he admits, he is “pissed about.”

The former long-time pastor hears critics who say he’ll be “playing God” if he takes an early exit from ALS. “Every time you go to the doctor, you’re ‘playing God’,” Dave counters.



COVID prompts need for increased communications

FROM EXECUTIVE DIRECTOR MARY EWERT



We have closed the books on FY 2019-20 and include an overview of financial activity on page 3 of this magazine.

FEN remains extremely fortunate in receiving bequests, both from members and non-members who support our cause. Please consider renewing your membership and donating online through the FEN website. This secure method is the most efficient and cost-effective route for your donations to be processed.

As we stay closer to home during the COVID pandemic, **FEN is ramping up its communications.** “[FEN’s 15 Conversation-Starting Favorites](#)” is on our website under “Resources – Books, Movies and Articles.” On page 6 is the story behind the list, which is aimed at triggering discussion about the possibility of actively ending one’s own life, the reasons one might consider that choice, and how different people with different values might approach such a decision.

I hope you find this selection, developed by volunteer Jim Van Buskirk, to be a valuable tool.

FEN has an important online partner in Dave Warnock, a former evangelical minister who now identifies as an atheist and was diagnosed with ALS. Dave mentions FEN in most of his podcasts, and his story is on page 7. Check out his Facebook page at <https://www.facebook.com/DaveWarnock.DyingOutLoud/> and his website at <https://daveoutloud.com>

Thanks to volunteer Lily Chambers, we now have a private group and a page on Facebook. We are honored that Derek Humphry selected FEN to carry on his successful ERGO news service (a brief summary of recent items is on page 15). And magazine editor Jay Niver is developing a list of reporters around the U.S. who routinely cover aid-in-dying stories. Jay also did a July podcast with Kimberly Paul, whose EOL initiative she calls *Death By Design* at <https://www.deathbydesign.com>

You can be part of this ramped-up communica-

tions effort. When you find articles of interest, email that information, including a link to the article, to

finalexitnetworkcontact@gmail.com. Your tip may appear on our Facebook page or news service.

On July 14, we stepped into the world of Zoom webinars with a session titled, “Know Your Enemy: Dementia – What to do Before and After the Diagnosis.” The program included information on Voluntarily Stopping Eating and Drinking (VSED) and FEN’s Supplemental Advance Directive for Dementia Care (SADD). This pilot program was offered to FEN lifetime members from Florida and New York. (See story on page 11.)

In closing, please know that FEN’s Exit Guide Program is adapting to the ever-changing threat that is the COVID pandemic. Guide travel is under constant review, and when travel resumes it will be with a custommized rather than “one size fits all” approach.

Although COVID is keeping us closer to home, technology is enabling us to deliver for FEN. *Until next time, stay safe, stay in touch.*



Annual Meeting Update

FEN’s bylaws require that it conduct an Annual Meeting of members. This meeting may be called at any time by the FEN Board of Directors and will be held at a time and place designated by the board.

For a number of years, the Annual Meeting has been held in July. This year, due to the COVID-19 pandemic, the July meeting has been postponed.

The Annual Meeting will be held when it is feasible to hold an in-person gathering. We will announce the meeting date on our website and through email.

HELP US KNOW: WHY MAY YOU WANT TO GO?

By Jay Niver, FEN Editor

What makes someone want to hasten their death?

Final Exit Network wants quantitative data to better understand what emotional, social, and cognitive issues – as well as physical ones – may prompt a person to seek a planned exit. We do not want to rely just on speculation or anecdotal accounts.

FEN's Psychosocial Research Committee has devised two questionnaires that FEN coordinators (who also contributed to its development and implementation) are now collecting when clients apply for Guide Services. The first instrument is the Quality of Life Impact Scale (QLIS), and the second is an optional research questionnaire.

The Medical Evaluation Committee uses clearly stated physical health criteria when screening applicants but is aware of their psychosocial impact, according to FEN President Brian Ruder: "These new survey results may help our understanding of what applicants are thinking and feeling about their situation.

"The hope is that FEN will be able to collect information that brings additional light into the American end-of-life (EOL) discussion."

"FEN is in a unique position as the only national EOL organization that can collect and report the thoughts and views of people who seek to accelerate their death," Ruder added, "even though they may not have an imminent terminal health diagnosis or a prognosis of less than six months to live."

"Careful, statistically based research data hopefully will allow FEN to move more from

the shadows into the center of the national EOL discussion," said FEN Executive Director Mary Ewert. "At the same time, it will increase FEN's credibility and respect as a central and mainstream right-to-die organization."

Ruder said this would not only allow FEN to speak with scientifically sound knowledge on proposed legislative issues, but also provide more public opinion support through growing respect for the organization's work.

So that FEN members may be more informed about the nature of this effort, the questions from the QLIS have been reformatted as a public survey and appear on the other side of this page. This is an effort to collect information from people who are not yet faced with an actual decision about hastening their death.

Ruder asked: "Do you think what is important to our quality of life when we are healthy will change when our health is profoundly and terminally compromised?"

"We encourage you to not only fill out the questionnaire and mail it back, but also to copy it and have family, friends, or neighbors fill it out so you can submit theirs as well."

This FEN magazine has a pre-addressed, postage-paid return envelope between pages 12 and 13. Fold and enclose your surveys in it (two can be mailed at the pre-paid rate).

"We hope to gather a robust amount of data," Ewert said. "The more we can collect, the more significant the results potentially can be."

No names or personal identifying information are on the survey, and any reporting of data will only reference total group responses.

Please complete and return the survey on the other side of this page!

Survey - Factors that might lead me to consider a hastened death

No personal identifying information is being asked or will be published about your responses. **Put one X on each row.**

	<u>Less Significance</u>	<u>Moderate Significance</u>	<u>High Significance</u>
Physical Issues:			
Significant loss of hearing or vision	_____	_____	_____
Inability to prepare food, climb stairs, or walk independently	_____	_____	_____
Continuous fatigue, incontinence, nausea, or trouble breathing	_____	_____	_____
Pain not well managed with medication	_____	_____	_____
Cognition and Memory Issues:			
Confusion, like getting lost, trouble paying bills, or difficulty comprehending reading	_____	_____	_____
Forgetting to take medicine, conversations, people you know, questions you asked	_____	_____	_____
Emotional Issues:			
Loss of independence or intolerable quality of life	_____	_____	_____
The lack of any further effective or acceptable medical treatment to improve your life	_____	_____	_____
Inability to create a meaningful life any more	_____	_____	_____
Having a six to 12-month prognosis for living	_____	_____	_____
Social Issues:			
Needing to move to a nursing home	_____	_____	_____
No remaining close friends, family or pets	_____	_____	_____
Running out of money or not wanting to give money to a nursing home	_____	_____	_____
Feeling like a burden to others	_____	_____	_____

Other Factors: _____

Age _____ Highest level of education _____ Spiritual identification _____ Do you have an
immediate life-threatening condition? Yes _____ No _____ Do you support the Death with Dignity movement?
Yes _____ No _____ **Please return in the self-addressed, pre-paid envelope enclosed in this magazine.**

Webinar focuses on dementia, broadens outreach



Dr. Tom Tuxill addresses online participants July 14 in FEN's first webinar.

Dementia – with all its challenging issues relating to the end of life – was the focus of FEN's first webinar, held July 14 via Zoom.

Board member and past president Janis Landis, who helped organize the event, said meeting online has become essential due to the coronavirus pandemic.

FEN had been phasing out its local affiliates to focus on broader outreach and education programs. "But the advent of Covid spurred us to using webinars for both internal and external communications," Landis said.

Appearing for FEN were Executive Director Mary Ewert, legal counsel Robert Rivas, Client Services Director Lowrey Brown, and Dr. Tom Tuxill, chair emeritus of the Medical Evaluation Committee.

They discussed the importance of choosing a strong healthcare surrogate; how one might rethink healthcare choices in the face of dementia; FEN's Exit Guide Program; Voluntarily Stopping Eating and Drinking (VSED); FEN's Supplemental Advance Directive for Dementia Care (SADD) and the associated litigation initiative (covered in the spring issue of the magazine).

New Jersey's Dr. Robin Plumer was an invited guest attendee at the inaugural FEN webinar.

Starting as an emergency room doctor, then shifting to hospice and palliative care, Dr. Plumer recently opened a medical aid in dying (MAiD) practice. Her state's Aid in Dying for the Terminally Ill Act went into effect in August of last year.

"It's great that FEN is encouraging the discussion of end-of-life options in dementia," said Dr. Plumer, "since it's terrifying for people who are newly diagnosed with dementia to anticipate the potential loss of autonomy."

As well as serving patients seeking MAiD under New Jersey's law, Dr. Plumer's practice provides medical support for those choosing VSED, and she has a particular interest in serving those facing dementia. Many of them do not wish to live into later stages of the disease, but they are not eligible for their state's MAiD law.

"Many people do not realize that dementia is a terminal illness," emphasized Dr. Plumer. "For those who fear subjecting themselves and their families to the indignities that are inevitable in the end stages of dementia, there are limited options."

When asked about her choice to specialize in MAiD, dementia advocacy, and VSED, Dr. Plumer said she strongly believes that patients should have the right to choose when and how they die with a terminal illness. "While hospice is wonderful with symptom management, some people choose to actively end their suffering before they become completely dependent on others," she added. "Patients with dementia do not qualify for MAiD, so they must be proactive early on."

As Dr. Tuxill noted, dementia is especially thorny for those who wish to shape the time and manner of their deaths. "Your brain is the tool you will use to choose an exit date and to carry out your plan, but your brain is the tool that is degrading," he said.

Board member Landis was happy with the response to the webinar. "We're already looking ahead to covering topics like advance directives, how to choose a healthcare surrogate, and how to be an effective surrogate," she said.

(Editor's note: To learn more about Dr. Plumer's practice, go to: www.compassionateendingsnj.com)



A TRAGIC TWIST OF FATE

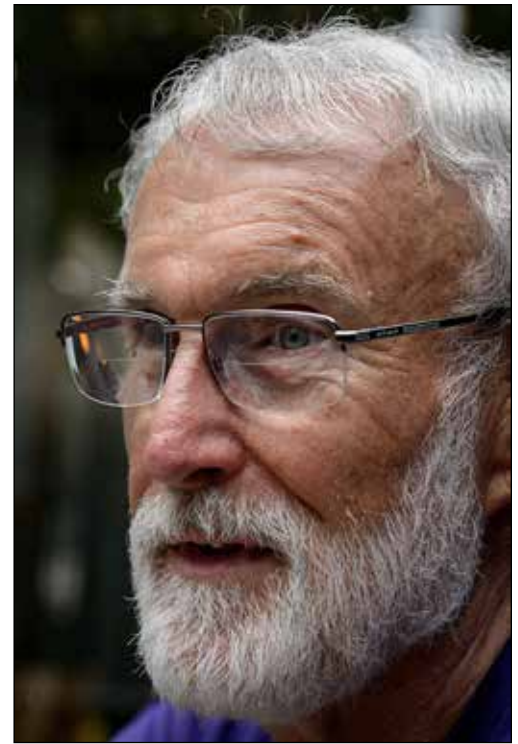
By Lowrey Brown, FEN Client Services Director

Peter was an Exit Guide since at least 2014 and had been a supporter of those choosing to control their deaths long before that. He supported many individuals through FEN, and, prior to FEN, had supported his parents when they were ready to end their lives.

New Year's Eve, bodysurfing, Maui. His forehead hit the sand. Hard. He knew instantly he had injured himself and moved to swim gently to shore ... *except that nothing moved*. His arms and legs didn't respond. He was face down in the water. He later told Liv, his former wife and dear friend, that he presumed he would drown there, but his elder son, Dane, reached him quickly.

Liv, Ty, Peter's younger son, and Maureen, Ty's wife, were a little way down the beach, but saw instantly that something was wrong. Liv describes sitting at Peter's side in the midst of the chaos after Peter had been carried from the water. She was holding his hand, but realized that his hand wasn't responding, and he didn't seem to know she was there, so she craned over to put herself in his view. The look he gave her is the kind that bores through you, leaving an invisible yet indelible track. Sadness. Sadness for her. Sadness for himself. And fear.

"This is my worst nightmare," he said, somewhere in the blur between beach and hospital. The eight days that followed were to be a roller coaster of reality, hope, disappointment, and decision. A surgery to



Peter Vennewitz

Liv had climbed into the hospital bed with him, her hand on his chest as it rose and fell, a little and then less, and then not at all.

clean his spinal column – it hadn't been severed – was followed by a few days of improvement and the hope he might regain some physical functionality. The damage, however, included the third vertebra, which affects breathing. He could breathe, but it wasn't exactly automatic.

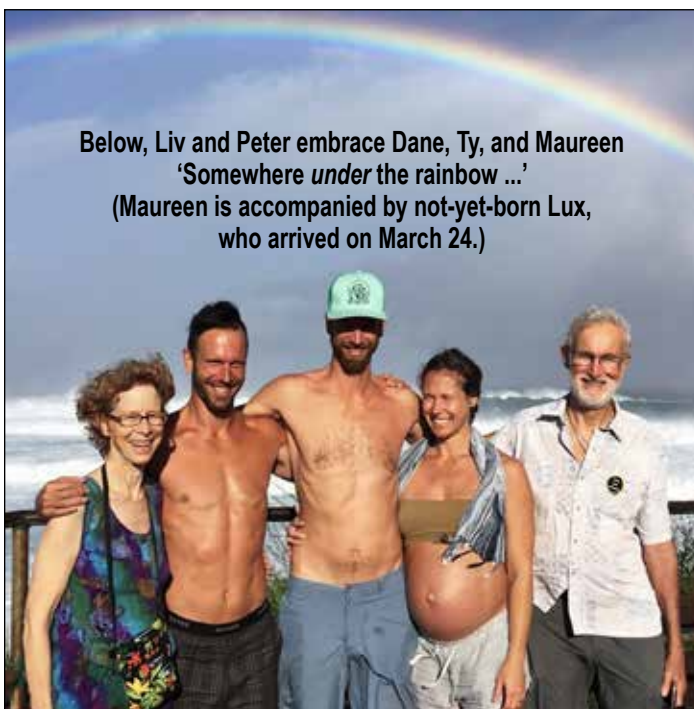
On Jan. 5, he told them they needed to have a family conference the next morning. In the middle of that night, exhausted, he blacked out and had to be put on a ventilator, which meant continual sedation because the tube goes down the throat and would trigger the gag reflex.

There could be no family conference with Peter.

The hospital was working to arrange an airlift to Portland. Peter's family showed up with his advance directive.

Peter was not an armchair philosopher: For him, values were inextricably tied to action. After the birth of Ty, he immediately got a vasectomy. He worked with Planned Parenthood, and this was something he believed in. Liv noted that Peter honored others' choices.

"Liv" was actually the name she had hoped to



Below, Liv and Peter embrace Dane, Ty, and Maureen
'Somewhere under the rainbow ...'
(Maureen is accompanied by not-yet-born Lux,
who arrived on March 24.)

TRAGIC continued on next page

Donate to FEN while you shop

It sounds too good to be true: two favorite pastimes at once, shopping and supporting a terrific cause – *at no extra cost to you!*

Especially during the pandemic, online buying has skyrocketed, and Amazon is the prime marketplace. You can shop elsewhere, but the AmazonSmile program will donate 0.5 percent of the value of your eligible purchases to Final Exit Network.

Half a percent doesn't sound like much, but by the time you read this, Amazon Smile will have donated more than \$185 million to charities around the world.

Make FEN *your* designated cause.

Visit smile.amazon.com and select Final Exit Network. Then, whenever you purchase from Amazon, order through the [AmazonSmile website](https://smile.amazon.com). Your purchases will contribute to our work and mission without it costing you one extra penny.



You shop. Amazon gives. It doesn't get much easier than that.

Eat Spam, don't curse it

Important emails, including messages from FEN, may not be reaching you because they go straight to "Spam" or "Junk Mail," where you won't see them



unless you check that folder.

A quick, easy fix is to add Final Exit Network to your "contacts" list. Do it on your computer, laptop, tablet, or Smartphone.

We'll supply more detailed information in the next edition of the FEN magazine.

TRAGIC *continued from prior page*

name her daughter, but when neither Dane nor Ty cooperated, she took the name herself, replacing the more common, "Kathy."

It might seem a small thing, but, 20 years later, she is still touched that Peter didn't resist the change and was the first to consistently use "Liv."

The doctor waved off Peter's advance directive, saying they would not rely on paperwork if Peter could speak and, after a tracheotomy, he could. That evening, a trach and feeding tube were put in. To allow for recovery, sedation was not withdrawn until the morning of Jan. 8.

By midday, Peter was alert, and the doctor explained that he was in good condition to be flown back to Portland. As the doctor turned and left the room, Peter mouthed to Liv, who was alone with him, "I want to die."

Peter had been thinking about end-of-life choice – not theoretically, not at arm's length, but intimately – both for himself and for those he supported through FEN. He had taken many a deep, hard look inside himself, so when the question came, he was ready.

That evening, after tears, after stories, after leave-takings, after so much love had been squeezed into that one little hospital room it might burst, the ventilator was disconnected. Liv had climbed into the hospital bed with him, her hand on his chest as it rose and fell, a little and then less, and then not at all.

We celebrate our country which let him choose. We celebrate his family who supported him in his choice. And we celebrate Peter for being the warm, vibrant man that he was and for sharing himself so unstintingly with us and with those we serve.



Good Endings Book Club



How to Die by Seneca

Reviewed by Huck DeVenzio

If you thought that intelligent discussion of right-to-die issues began recently with development of medical technology and the advent of life-prolonging gadgetry, you'd be off by about 2000 years.

See, this book, written by Roman Stoic philosopher Seneca (4 BCE - 65 AD), covered death in eight volumes, compiled here in one book translated by James S. Romm.

The Stoics used their minds to interpret nature's path. Seneca makes such thought-provoking and timely observations as:

...fear of death not only makes dying more difficult but diminishes the nobility and moral integrity of all of life...

He lives badly who does not know how to die well.

...Know that the same outcome awaits us all, but dying fearfully, often, is itself a cause of death.

He who fears death will never do anything to help the living.

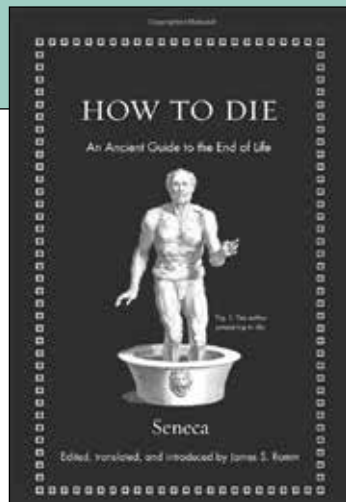
There's no difference between the longest life and the shortest life, if you survey how long a person lived and compare it with how long he didn't live.

...it matters how well you live, not how long.

...you're a slave to people, to things, to life (for a life lived without the courage to die is slavery).

...it's a fool who lives for pain's sake.

"Just as a longer life is not necessarily better, a longer death is necessarily worse."



While Seneca did not address MAiD explicitly, and his comments on self-deliverance are rather ambiguous, his view seems clear. He accepted self-liberation by suicide. Several of his colleagues had suicide forced on them by greedy emperors; Seneca himself met his end in this way, imposed by Nero.

This book is slim and easy reading for a book on ancient philosophy. If you wish to make it more challenging or test your high school education, the text is presented in Latin as well as English.

Truman Movie 1:48 (Spanish, 2017)

Reviewed by Lalit Gupta

Warning: It has English subtitles (not injurious to health).

It is NOT a documentary on the 33rd President. It IS a movie that many FEN members may enjoy, and nod their heads in recognition and understanding as it unfolds.

It deals with end-of-life decisions, and involves two childhood friends, old and greying now. The arrangements to be made; the secrets; the verbal Jiu Jitsu; the prevarications in trying to hide the truth are all shown in a gentle and non-judgmental manner.

This is not a spoiler: Truman is the name of the dog of the dying man. *What to do with this beloved pet?*

Humor is interwoven with the sense of inevitability. It is full of poignant moments and small, unexpected revelations. It shows well how the people close to a dying person are so different in their responses.

Fans of foreign cinema will recognize the two lead actors from many other Spanish films. Natural acting at its best, they make it look so easy. Their on-screen rapport and badinage are a delight to watch.

The ending came as a surprise to me. My wife claimed that she had seen it coming. She is much smarter than me.

Available from streaming services and distributors.



THE BACK PAGE

A COMPENDIUM OF RIGHT-TO-DIE WORLD NEWS

New Zealand

New Zealanders will decide on Sept. 19 whether to legalize voluntary euthanasia, ending years of heated parliamentary debate on David Seymour's End of Life Choice Bill.

Voters will cast ballots in a binding referendum as part of their general election after the country's parliament voted in favor 69-51. The law would allow terminally ill people with less than six months to live to choose assisted dying if approved by two doctors.

Prime Minister Jacinda Ardern has supported calls for euthanasia reform, and a recent poll suggested 72 percent of New Zealanders support some form of assisted dying.

There have been some alterations to the legislation. It now only covers those diagnosed with less than six months to live, while it previously included severe and incurable conditions.

United States – California

- The California Department of Public Health in July released its annual report on the state's End of Life Option Act. It suggests that the law is being used appropriately.

In 2019, 618 people received prescriptions and 405 used them. The median age was 76, and nearly 70 percent had cancer. Many others had diseases like ALS or Parkinson's.

The bill's co-author, state Sen. Bill Monning, said he knows of no complaints of abuse or misuse or tragic consequences during the law's first four years.

- *Los Angeles Times* columnist Nicholas Goldberg argued in July that California's MAiD law should be expanded to include those who suffer from dementia.

"We should make more people eligible to participate," he wrote. "Alzheimer's patients and others facing dementia seem like an obvious place to start."

Goldberg said policymakers also could "consider people with certain degenerative diseases or those living in chronic pain, even if they aren't within six months of death."

"People often behave as if anything that hastens death is morally unacceptable and that fighting to extend life is always preferable. But there are fates worse than death," opined the columnist.

The Netherlands

Parliamentarian Pia Dijkstra this summer submitted a legislative proposal to allow elderly people who feel they've come to the end of a complete life to ask for euthanasia.

The controversial bill is causing some strife among political factions, with especially the two Christian parties being vehemently against it. The proposal allows people over 75 who have a persistent wish to die to ask for euthanasia.

"There is a group of elderly people who have finished their lives. They say: 'I go to sleep every night with the hope that I won't wake up again.' I want to make euthanasia possible for that group under strict conditions," Dijkstra said.

Australia

- An unusual RTD advocate group has cropped up in Queensland.

The Electrical Trades Union (ETU) is mounting a statewide campaign to back Voluntary Assisted Dying (VAD) law reform. The extensive social media campaign is based around former ETU state secretary Peter Simpson, who is fighting stage-four melanoma.

The union is seeking action on law reform before the October state election and is asking for a commitment from Premier Annastacia Palaszczuk to act quickly on the findings and recommendations of the Queensland Parliament's inquiry into VAD, conducted by the cross-party Health Committee.

The ETU's efforts include an online petition calling on the state government to have VAD laws debated and passed by the Queensland Parliament before the elections.

- In July, Victoria's Voluntary Assisted Dying Act marked its first year in effect, and it appears to be functioning reasonably well.

It is not known how many Victorians used the law to end their lives, but about 400 people made inquiries (the first step to assisted dying) – about double the number expected. Some logistical and bureaucratic issues remain, and COVID-19 has complicated things.

The Victorian law was adopted after a prolonged, intense, and divisive public debate.



Bequests make exits possible

Bequests have always been the biggest source of income for Final Exit Network. Last year, almost 35 cents of every dollar in the FEN budget came from a generous donation by someone who remembered us in their will.

Now it's even more clear: For our just-finished fiscal year, more than 56 cents of every operating dollar came from bequests. Put simply, were it not for supporters' dying gifts, it would be hard for FEN to exist.

Sometimes, those contributions are from members or others who have been helped by our Exit Guide Program (membership is not required to use our services). Others who have never joined or participated are letting FEN continue its mission in support of others at their end of life.

In any case, it is a way to “pay it forward” and ensure that others in similar situations can find a peaceful, dignified “exit” when it's time.

Please, *remember us in your will or name FEN as a beneficiary in your IRA or other financial product.* It's easy and requires no lawyer. All you need is our tax ID (80-0119137) and address: FEN, POB 10071, Tallahassee, FL 32302.

We'll be happy to answer any question if you call toll-free: 866-654-9156.



Educator joins board

FEN welcomes Socratic method (not his hemlock)

Adam Rose joined the FEN Board of Directors following a unanimous approval vote of the board at its July 23 annual meeting (held online).

Originally from the New York area, Adam has lived in Chicago for the past 30 years where he has devoted his career to “helping individuals, groups, and organizations think more clearly about themselves and the world around them,” he said.

He does so primarily as a teacher and administrator of *Great Books* Socratic Method seminars for adult and undergraduate students of diverse ages and backgrounds.

For the past five years – and certainly since the beginning of the COVID-19 pandemic – most of his teaching has been online with students participating from around the world.

Adam became interested in end-of-life/right-to-die issues in 2016 when a friend of his was diagnosed with ovarian cancer, and he has been a FEN volunteer since 2019. Divorced with no children, Adam enjoys working out and learning to ballroom dance.



Adam Rose