

FINALEXIT™ NETWORK NEWSLETTER

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SUPPORTING THE HUMAN RIGHT TO A DEATH WITH DIGNITY

www.finalexitnetwork.org

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Dr. Larry Egbert, Jr.

A hero to those of us who knew his contributions.

Dr. Egbert standing outside of the Atlanta Supreme Court right after the Court declared the Georgia statute unconstitutional.

BALTIMORE, Maryland, June 9, 2016

By Robert Rivas, FEN General Counsel

Dr. Lawrence Deems Egbert Jr., the former Johns Hopkins anesthesiology professor and crusader for the right to death with dignity, has died of heart failure. He was 88. He is survived by his wife and staunch supporter, Ellen Barfield.

Dr. Egbert was known as “Larry” to his friends and colleagues at Final Exit Network, but *Newsweek* dubbed him “the New Doctor Death” after the passing of Jack Kevorkian.

He devoted his career to humanitarian causes. As a young doctor, deeply offended that anesthesiologists used their skills to put condemned prisoners to death, he campaigned against the death penalty. In his last job before retiring, he worked for Doctors Without Borders. After retirement, he volunteered for Doctors for Human Rights, examining the victims of torture by foreign governments to document their physical and psychological scars.

Dr. Egbert was Final Exit Network’s medical director from its founding in 2004 until he was

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“He was unequivocal in his beliefs about the Final Exit movement, insistent on telling the truth about his feelings and his conduct, and unwavering in his certainty that the criminal justice system would ultimately vindicate him.”

- Don Samuel, Dr. Egbert’s defense attorney

arrested on February 25, 2009, the infamous day when the Georgia Bureau of Investigation initiated an unsuccessful effort to destroy the organization—and perhaps him as well.

Georgia’s indictment was followed by indictments in Arizona and Minnesota. Dr. Egbert was resolute and even cheerful throughout nearly eight years of fighting the charges.

He died without compromise or a criminal record. During this time, he lost his post on the Johns Hopkins faculty and his license to practice medicine in Maryland, but was never shaken in his belief in the rectitude of his conduct.

“Only a very few people have the courage, compassion and energy that defined Dr Larry Egbert,” said Final Exit Network’s president, Janis Landis. “But everyone who had the privilege of knowing and working with him has been inspired to try, to the best of our abilities, to emulate his example and honor his memory. He was and will remain a yardstick to measure ourselves against.”

His defense attorney in all three states, Donald F. Samuel of Atlanta, said: “Larry Egbert was the most extraordinary person I have had the privilege of representing. He was unequivocal in his beliefs about the Final Exit movement, insistent on telling the truth about his feelings and his conduct, and unwavering in his certainty that the criminal justice system would ultimately vindicate him. I will miss him as a client, a friend, and an inspiration.”

In the first case, in Georgia, the GBI charged Egbert, the Final Exit Network corporation, and others with “racketeering,” which theoretically could have led Dr. Egbert to be imprisoned for the rest of his life. In 2012, however, the Supreme Court of Georgia struck down the Georgia statute as an unconstitutional restriction on the right of free speech in violation of the First Amendment. As a result the GBI had to dismiss all the charges.

In Arizona, Dr. Egbert and a Final Exit Network Exit Guide, Frank Langsner, went on trial in 2011 on charges of assisting in a suicide. The Phoenix jury found Dr. Egbert not guilty, but was unable to reach a verdict as to Langsner.

When the judge told Dr. Egbert he was “free to go now,” Dr. Egbert turned to his lawyers, Don Samuel and his associate Kristen Novay, and asked, “Isn’t Frank free to go now, too?” The attorneys whispered to him that Langsner was still subject to a possible retrial.

He suddenly jumped out from behind the defense table and exclaimed to the judge, “I object!”

Novay gently pulled him back to the defense table. “I never thought I would live to see the day when a defendant objected after a jury found him not guilty,” Samuel said. Novay said it “was an honor to defend a man who consistently defended the rights of others.”

Using information seized in its investigation, the GBI communicated with scores of law enforcement agencies across the nation, trying to foment charges against the Network over exits in other jurisdictions. The GBI’s efforts to “dismantle” the Network—as the lead agent termed it in an secret internal memo later uncovered by Egbert’s lawyers—were a complete failure except in Dakota County, Minnesota, where a notorious publicity hound of a prosecutor secured yet another indictment of Dr. Egbert.

So long as charges were pending, Dr. Egbert was unable to serve the Network in any capacity. Between the Georgia, Arizona, and Minnesota cases, charges were pending from 2009 until Dr. Egbert died.

The Minnesota case dragged on and on. By 2016, the State’s case against Dr. Egbert was so crippled in pretrial proceedings that it appeared highly unlikely he would ever be brought to trial, yet the prosecutor kept Dr. Egbert nominally on the hook, refusing to perform the formality of dismissing the charges. The charges were rendered moot by his death. ■

David Edward Denton 1935-2015

With his carefully trimmed goatee, long gray ponytail, and pipe in hand, David looked like what he was: a philosopher, a graduate professor, and a published author. He had a “conversation” with everything he read making marginal notes in each journal, magazine, newspaper, and book as he played with words and theories and philosophies. One knew when he was having fun by the twinkle in his eye and the slight smile on his face.

David was not happy unless he was in dialogue. He wrote: “I dwell on that thin line between order and chaos, the Apollonian and the Dionysian, the Classical and the Romantic, the Liturgical and the Pentecostal—and, holding that dynamic of dialogue is pleasure.”

Perhaps, in death, that dialogue has taken another form that he couldn’t even in embodied life imagine. Perhaps that “thin line” between life and death has merely enhanced the interconnectedness of which he wrote and lived. Perhaps he has playful pleasure.

That is what I, Kathryn, his beloved partner of 27 years, choose to believe. David died suddenly and unexpectedly last October in his bed not far from his treasured old tulip tree outside our historic Kentucky home. He had a good death. The last 12 years of his life he spent 6 months of the year in our Intracoastal home on Hilton Head Island, SC and to there his ashes will be returned.

David was not afraid of death. He’d come to terms with his mortality in the 1980s when



Alan Mittelsdorf recently died and left a generous legacy to Final Exit Network. He is shown here with his wife Jeannette. We are grateful to the Mittelsdorfs for honoring us with a gift that will enable us to extend important programs and continue our efforts to provide our exit guide services to those who are suffering and educate individuals on the possibility of a peaceful death.

he was supposed to be dying of cardiomyopathy. With his will and legal papers, he left a translated copy of a chapter from Seneca’s Letter 70: Moral Letters to Lucilius, “In the Proper Time to Slip the Cable.” On page 294, he had underlined: “And dying well means escape from living ill.”

David was an early supporter of the Hemlock Society. As it developed and changed, he kept in touch. At his death, he chose to leave a gift to Final Exit Network to support education and assistance.

There are thousands of falling leaves
in the air,
And I am running to catch them
in one hand.
Finally, I fall, exhausted,
And find them coming
to my lap.

— *Existential Reflections on Teaching*, by David Denton (pg. 31). Other works: *The Philosophy of Albert Camus* (1967), *The Language of Ordinary Experience* (1970), *Existential Reflections on Teaching* (1972), and *Gaia’s Drum: Ancient Voices and Our Children’s Future* (1991). ■



“Since Medicaid does not support PAD, we had to pay the full cost of the drugs out of pocket. The cost was \$3500.00, which is outrageous.”

Curt's Story

An experience with Physician-Assisted Dying

By Cary, Cindy, Sharon, Chris, Will, Debbie, and Katy

The existence of a PAD law is no guarantee of a death with dignity, as this story reveals

This story is about my family's experience with PAD (Physician-Assisted Dying). Our hope is that it will be of some help to others following, or contemplating following, the same path.

In the fall of 2015 my brother, Curt, age 62, was diagnosed with incurable prostate cancer. He was skin and bones, couldn't walk, and suffered from hallucinations and vision issues as well as bone and joint pain. The hospital doctors held no hope for curing the cancer. We were very lucky to secure for him a bed at a hospice facility in a state in which PAD is legal. I cannot say enough about how wonderful and supportive the hospice people were to Curt and the rest of his family, and we all feel a huge debt of gratitude for their efforts.

I am not naming this facility or state because, though everything they did was perfectly legal and above board, the staff exhibited a desire to fly under the radar regarding their participation in the process. This position reinforces the reality that PAD is still a controversial endeavor politically, religiously, or otherwise.

Curt had been a very independent and self-driven individual all his life. His greatest fear was becoming completely bedridden and unable to perform even the most basic personal behaviors. Knowing that death was inevitable, he asked his two brothers (Chris and Cary) and their wives (Sharon and Cindy) to support him in pursuing permission from the state for PAD. It was his one way of feeling he had some individual control over both his life and death at a time when he was helpless in virtually every other area.

We succeeded in obtaining that permission and sometime later Curt announced that he wanted to follow through. In this state the medical department which oversees hospice centers will assist in the paperwork and the approval process and coordinate the prescribing of the drugs, but the exit cannot take place in one of their facilities. It's up to the family to make other arrangements. This begs the questions, "What if there is no family to step in and help?" and "What if the family is divided on the issue?"

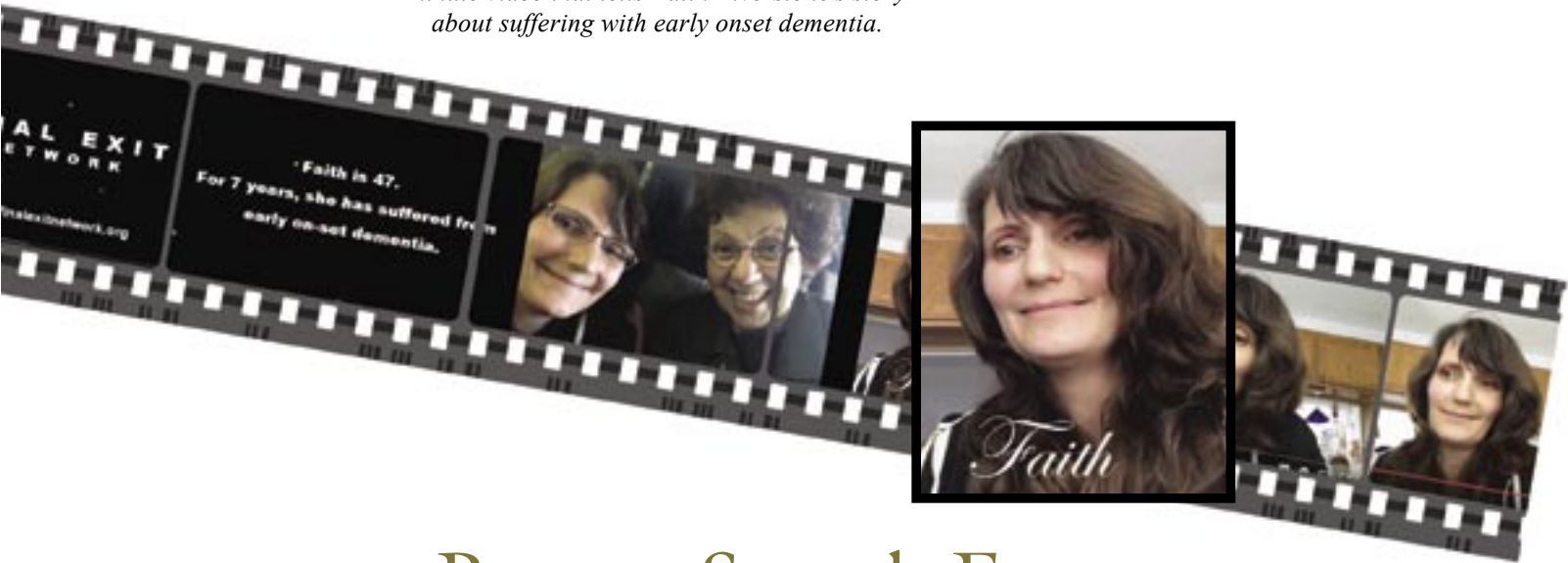
My brother and I, along with our spouses, were unified in our desire to facilitate Curt's wishes. We arranged for Curt to be released from hospice and we moved him to my brother's home. We obtained a prescription for 100 Seconal tablets.

Curt was living on social security and being supported medically by Medicaid. Since Medicaid does

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Visit [youtube.com](https://www.youtube.com) and search for "FAITH in Minnesota Final Exit Network" to view the 12-minute video that tells Faith Riverstone's story about suffering with early onset dementia.



Ban on Speech Forces Minnesota Woman to Leave State

By Julia Hanway

Faith is losing her mind. And she knows it. Faith (a Minnesota resident, who prefers to use only her first name) has a degenerative brain disease and she well knows the consequences she faces as it progresses. Her doctor has spelled out its brutal effects and she is making plans for her future. In Minnesota, however, she cannot even talk to anyone about one of her options, which may be the one that is most attractive to her as her slow mental decline proceeds.

This spring, due to a Minnesota court's ruling in August, Faith was forced to travel to another state, in this case North Carolina, to learn about "peaceful self-deliverance" from a Final Exit Network volunteer. Faith's options are few and, though self-deliverance is hardly ideal, Faith wanted to learn about it as it may be the option that holds out the most hope for her to have a death with dignity. Furthermore, she strongly feels she has a right to know.

For now, restricted by an interpretation of a law unique to Minnesota, Final Exit Network is banned from speech that would enable Faith to learn about the process in her home state.

As Faith researched her options, she found that a death with dignity might be preferable to her life-

draining illness. She fears languishing for years in an institution, locked in the Alzheimer's unit in a facility she does not recognize, tended by nurses and doctors that she does not know, who will have to take care of her every personal need.

Final Exit Network is one group that could talk with her about peaceful self-deliverance, but not in Minnesota. FEN has been banned by the Minnesota courts from even talking about it to its own 80 in-state members. In August, FEN was "convicted of speech that enabled a person to commit suicide." The Network was fined \$33,000 for "assisting in a suicide" for educating a woman with information she used that led to her death. Never mind that the same information is in books readily available in bookstores and libraries in Minnesota and on the Web.

An appeal has been filed but, for now, FEN volunteers risk a 15-year jail sentence if they go to Minnesota to educate Faith as to how she might end her life. So, Faith left Minnesota, accompanied by a Network Exit Guide, in order to exercise their freedom of speech elsewhere.

You can see Faith explain her situation in a 12-minute online video. Go to [youtube.com](https://www.youtube.com) and search "FAITH in Minnesota Final Exit Network." ■

*“Finally, twenty-three hours after taking the drug
Curt quietly stopped breathing.”*

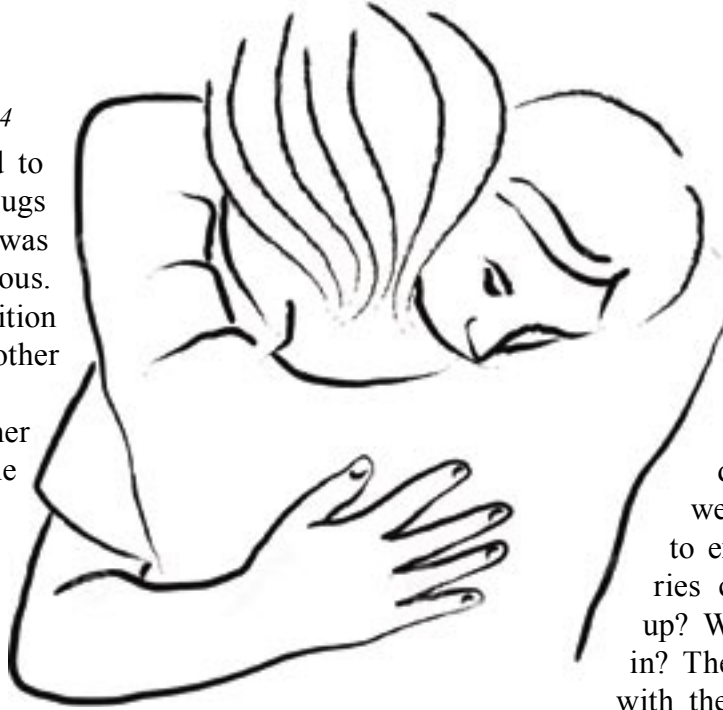
CURT *cont'd from page 4*

not support PAD, we had to pay the full cost of the drugs out of pocket. The cost was \$3500.00, which is outrageous. Luckily, we were in a position to swing the cost. Many other people wouldn't be.

We had a last nice dinner with Curt knowing that the next day he would consume the drugs and die. How can I describe the anxiety of waiting and knowing what would happen the following day? What time of day would we do it? We needed to plan ahead so the hospice nurse could be available both in case something went wrong, as well as to witness and pronounce death. None of us wanted to pressure Curt into deciding on a specific time. But Curt, bless his courageous soul, announced that we should plan on 5:00 pm.

Hospice had provided us with very specific instructions for the administration of the drug and what to expect following his ingestion of it. We were to administer anti-nausea medicine one hour prior to the lethal drug to prevent him from vomiting it up. We were instructed to empty the Seconal capsules into enough water to make a drink the consistency of a slushie. We were told that he must consume it all rather quickly and that within a few minutes he would become unconscious. Death would occur between one and five hours thereafter. Or so they said.

The hospice nurse graciously remained in his car while we administered the drugs so as to keep it a family-only event. We gathered around Curt, saying goodbye and holding him. As Sharon put it, you could cut the love in the room with a knife. Curt downed the liquid though it was a struggle because of his weakened condition and because it had a bad taste. Within a couple of minutes he went into a coma. We stretched him out on his bed and proceeded to cope with the event each in our own way.




The hospice nurse came in and took his vital signs and we proceeded to wait. For me this was the worst. The wait was excruciating. We became more and more concerned as the hours passed and he didn't die. The five hours we were told was the longest time to expect came and went. Worries crept in. What if he woke up? What condition would he be in? The nurse consulted by phone with the doctor. They were clearly at a loss and in uncharted waters. All

night long we kept up the vigil with nobody getting much sleep.

Finally, twenty-three hours after taking the drug, Curt quietly stopped breathing.

In addition to the feelings of grief you might expect, one of my overriding feelings was frustration and, to a certain extent, anger that the whole process couldn't have been done more humanely both for Curt and his family. In this age of modern medicine using a decades-old barbiturate, making him drink the noxious substance, and making us all go through the waiting period seems so uncaring and pointless. There's got to be a better way. It's pure politics that there isn't. It seems to me that if it's legal there should be no roadblocks to finding the safest, quickest, and most humane method for administering PAD. If you were a death row inmate you'd likely have an easier time than did Curt.

PAD is obviously appropriate only in certain dire circumstances and then only after the process has been fully understood and accepted by those involved. That said, it is my hope that the process can come out from behind the woodwork and be looked at as a potentially wonderful and liberating alternative to a slow and agonizing death. Only when it does will more reliable methodologies become available. ■



Like many members, FEN member Rich, who suffers from an inherited, debilitating neurological disease, joined FEN because he supports death with dignity.

Why People Join FEN

Why do people become members of Final Exit Network? Just as interesting: Why don't more people join?

There seem to be four main reasons why members have joined FEN. They were motivated by one or, more likely, a combination of the following:

1. To partake of exit services.

For anyone considering putting an end to their suffering, membership in FEN is a sensible move. The application process and the consultation with exit guides provide practical information. Hastening your death, even when suffering, is obviously an enormous decision, and it makes sense to consult with trained people who can discuss the details of methods, legalities, effects on loved ones, and fulfilling your wishes, among other aspects. We usually don't make a big decision—on investments, buying a home, or even where to go for a vacation—without checking with an experienced consultant. No decision is as irreversible as self-deliverance, so people join FEN for reliable advice.

Membership also makes sense for those diagnosed with a terminal or degenerative disease, even if an end is not imminent and the members may never use FEN's exit services.

Through FEN they can keep abreast of developments in the death with dignity arena, enabling them to make judgments best suited to their own desires and situation.

2. To support a safe harbor for the future.

Most members do not need exit services now, but want to make sure that such services are available to them should a need arise at some future time. By joining FEN now, their contributions make it more likely that this "safe harbor" will continue to exist. Just as life insurance provides some protection against an untimely death, FEN membership is death insurance against a prolonged life.

3. To provide a means for others to get loving attention instead of a miserable death.

This is the altruistic reason for joining: You not only want to avoid suffering yourself, but you do not want anyone to have to suffer against their wishes.

4. To take advantage of the tangible benefits.

Members are eligible for several items with value. Most notably, you have an opportunity to register with the U.S. Living Will Registry,

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a database where people store advance directives and organ donor information. The document can be accessed by you and by healthcare professionals, increasing the probability that your desires will be found and heeded. For more information, see page 12.

You also receive this newsletter and other communications which will keep you informed of developments in death-with-dignity legislation, alternatives, proposals, arguments, and meetings.

* * * *

Members tell why they joined

“Dying of cancer, my mother asked me to see if Hemlock Society offered any options for her. She did not benefit, but it led me to be a member of FEN from its beginning. And I have since told others about FEN.” — *Robert W*

“As a young nurse many years ago, I watched a few patients die in agony and pain, and decided then that no one should have to die that way. Along life’s path I also realized, through observation, that there are many valid reasons for wanting to end one’s life, primarily due to incapacitation, illness, loss of mobility and ability to care for oneself, and too often the addition of humiliation, isolation or other demeaning

I knew I’d never want to suffer for a long time as two of my loved ones had.

factors. So I helped form a southern Oregon affiliate of FEN, whose membership I have enjoyed since the Hemlock days, because self-determination seems to me to be a basic human right.” — *Dee E*

“I was a member of Hemlock Society for years, but then lapsed as life and family got the better of me. My mother died badly in hospital and, when I searched for Hemlock, I found Final Exit. FEN suited me better philosophically and politically than Compassion and Choices, though I think what they do is great.” — *Laurel D*

“A major injury years ago put me in great pain and made me realize that I would not want to continue living my life if that kind of pain were the price.

Fortunately an operation put me back on the path of living well. A few years later, my mother died, peacefully at home in no pain. I learned to be grateful for my mother’s peaceful death and pondered my own.

That led me to do volunteer work for a hospice, visiting dying patients. My first and most memorable assignment was a man called L., a professional

truck driver. He was miserable, angry, harsh, ungrateful, and in denial. He was also in pain and literally without a relative or friend in the world. Because he was indigent and friendless, his facility and care were substandard, far below what I would ever want for myself.

“The cumulative effect of these and other experiences illuminated and reinforced my hope to have a death I could look back on with satisfaction. Above all, I realized I wanted to die pain-free and with as much control as I could. To have control over my dying process is just a continuation of how I have always lived. It is simply the last decision in the living process, and we all should have the right to create and direct the last act. [FEN] supports this basic right and works to create the conditions that allow for dying with dignity.” — *John T*

“As two loved ones were perishing, I made a tacit promise to them that I would do everything in my power to change the way terminally ill humans are treated. I believe working with the [FEN] organization is a good start.” — *Jean O*

“From 1974 to 1976 I lost three grandparents and a father-in-law. One died in the arms of his daughter, but another died alone in the hospital, both after suffering with cancer for years. The other two died in their sleep after short illnesses. I knew I’d never want to suffer for a long time as two of my loved ones had.

“In the 1990s my favorite aunt died from cancer. She chose a hospice where her compassionate doctor kept her comatose until she finally passed on. For me, it was an example of just one more way of dying that I would not choose for myself.

“Final Exit Network is the only American right-to-die group that will offer me information and stand by me with their supportive presence, in any one of the states that has not yet legalized physician aid in dying.” — *Renee N*

Up Close and Personal – that’s FEN

There are several Death with Dignity groups in existence—national, local, foreign. Nearly all of them focus on changing laws or regulations which restrict end-of-life options, and they try to do so through lobbying, organizing, and educating. They look at the long-range picture. Their objective is certainly worthy. Go get ‘em, guys.

But that’s not the niche of Final Exit Network. We’re the personal side of DWD, and the more immediate side. Instead of taking on government issues, we are concerned with individuals; we support suffering people with information and care, helping them to understand their options. FEN sends trained, compassionate exit guides into the homes of members seeking a peaceful, dignified death.

Furthermore, we serve people who are expected to have more than six months to live. A six-month prognosis is a common requirement, even though it is widely recognized that, by the time life expectancy falls to six months, a patient with a slow degenerative disease such

as Alzheimer’s, Parkinson’s, or ALS may have suffered for an extended period and may not be able to perform the steps needed for a legal self-deliverance.

That brings up a misconception about Final Exit Network. We do not undertake activities that exceed the limits of applicable laws, even when this might be the wish of a member.

If the other DWD groups are successful in their lobbying, more options will be open to our members, and that would be very desirable.

FEN members are committed to spreading the word about death with dignity: Fran Schindler, volunteer and dedicated exit guide, took to the road to the Reason Rally in Washington, D.C., the largest gathering of Free Thinkers in the U.S.



“As a teenager, I saw my mother slip away into the grips of Alzheimer’s Disease and saw how it tore up our family. After five years of her not knowing anyone in the family, she had a stroke and was rushed to the hospital, only to receive treatment that allowed her to “live” five more years, in a vegetative state. My mother’s illness was not covered by any insurance.

30 years ago as my mother begged me to end her pain and suffering.

My father had to go into bankruptcy and his coping was alcohol, which led to his early death. There were no support groups related to Alzheimer’s disease in the mid 1970s. There was no support or direction provided by any of her physicians. I vowed at that time to do whatever I could to understand why there was poor end of life care and no education for our family. I became a Registered Nurse and set a course for myself to educate families about choices for acceptance or refusal of health care and choices related to the end of life. I joined Final Exit Network to learn how

to encourage others to have the difficult discussions before a crisis hits and how to educate others about opportunities to have compassion at the end of life so one can have a death with dignity.”

— Jerry W

“My awareness that there must be a better way to die began 30 years ago as my mother begged me to end her pain and suffering. She had made me promise long before there was a need. However, when the time came, I was powerless. Work and a busy life followed. My involvement with Final Exit started when a good friend of mine who was a member asked me to be in a meeting with him and a representative from the Network to discuss his end-of-life wishes. I still have the letter he wrote to me on his final day.”

— John F

“There is nothing more precious or personal than how an individual elects to die. Happily, Final Exit Network is playing a significant role in this magnificent movement.”

— Gary M

DEPRESSION PROGNOSIS IS NOT ROSY

A Letter to the Newsletter

My heartfelt thank you to Lowrey R. Brown for writing the piece on Depression and to Final Exit Network for publishing it in the May issue of the newsletter. Severe depression has been the persistent elephant in the room in our discussions of assisted suicide. Whole armies of professionals and volunteers have mobilized to bring about the legalization of assisted suicide for people who suffer terribly from physical ailments. The severely—and long-term—depressed are ignored.

Our common belief that depression can be controlled, if not cured, with professional therapy and antidepressants is just another side of the coin that has stigmatized this disease for centuries. It's true that occasional depression, due to adverse life situations, and even chronic depression can respond effectively to those treatments. That is the good, the very good news. The bad news is that for a certain percent of people, depression is deep and ingrained for decades, rendering them increasingly hopeless, fearful, and heartbreakingly sad.

Here is a recent email: "Please help me die. This pain is unbearable. I dread and hate every hour ahead of me. All is dark. I'm begging. There's no one else. Really ... I realize ... There just is no one ... I'm alone. There is only me and the last task of suicide."

The writer of that email is my son. I have received hundreds of messages over the years that are filled with pain, pleading, and anger as he has struggled to find a way out of this pit, this hell. Psychiatrists, psychologists, drugs, drugs, and more drugs. The fact that he has kept on living, day after day—he is now in his mid-50s—keeping up what he calls his "disguise" that hides the darkness within—makes me both sad and proud. But now he is exhausted. Another email: "Please.help.me.die."

My heart aches. Should I help him die? How could I help him die? Why can't I help him die? Because I cling to hope that something will change. I keep remembering the good times, the walks, the talks, the hugs—when the "disguise" works and he forgets for a while what it's like when the darkness comes. I love him so much, and it's tearing me apart. Why is there no other option for him? Would he take it? I don't know. Would just knowing there is a helping hand bring some peace? Perhaps.

Don't let these people be forgotten. ■

— *A Mother*

Welcome to the Inten\$ive Care Unit for a Medical Death

Spread the Word

A good suggestion from Renee Neumann

Your local public library probably has stacks or newsstands of free newspapers and magazines. And libraries tend to be patronized by more educated and progressive people who are likely to espouse the idea of death with dignity. Leave your old issue of the FEN newsletter there (when the new one comes out) and it will likely be quickly be picked up by an interested reader, and possibly result in a new member. [Note: If you would like additional copies for distribution, let us know.]

WF Conference Held in Amsterdam



Faye Girsh

Every other year the World Federation of Right to Die Societies, a 36-year-old organization comprising 40+ right-to-die groups around the world, meets to consider worldwide issues. In May, the WF met in Amsterdam. FEN was well-represented by President Janis Landis, Advisory Board member and former WF president, Faye Girsh, and FEN's Medical Director, Richard Cone, MD. Girsh chaired a segment in which Dr. Cone presented a statistical analysis of the way Nitrogen works. Girsh was

also the recipient of the Marilyn Sequin Award for her contribution to the right-to-die movement internationally.

Complications in California

By Faye Girsh

On June 9 the California End of Life Option Law went into effect. Much like the Oregon, Washington, and Vermont laws, a mentally competent, terminally ill, California resident 18 or older, may ask a doctor for a prescription for

FYI continued on page 12



Approaching a Tipping Point

By Huck DeVenzio, Newsletter Editor

Nearly every new movement progresses through similar steps. First, people must be persuaded, usually through a frustrating series of hard-fought battles resulting in occasional, small victories. Over time, when persistence backs a worthy idea, the small victories become more frequent and more significant. Eventually, there comes a tipping point when the concept propels itself. Momentum favors the change rather than the status quo.



Huck DeVenzio

The Death with Dignity movement has not reached its tipping point. We still revel in small victories. But, I wouldn't want to be our adversaries—they face a swelling tide. An aging populace. Public opinion polls. Legislation in California. Funding for medical conversations. Canadian Supreme Court decision. Coverage on 60 Minutes. Editorial in the Journal of the American Medical Association.

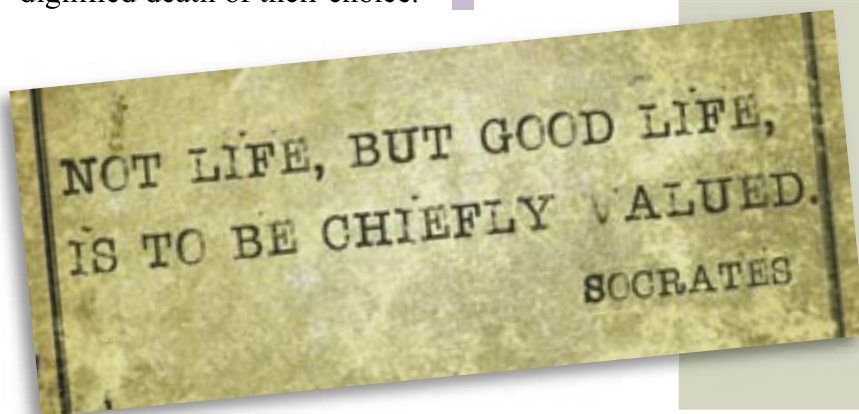
There will likely be more frustrations for DWD advocates, and legislation will not come soon enough for all of us. Nevertheless, we can take heart: We're closing in on the tipping point.

FYI continued from page 11

a lethal dose of medication. There is a 15-day waiting period with three requests required during that time, and a second doctor must affirm the competency and terminality of the person. Though not specified by statute, the medication usually has been 9 or 10 grams of a fast-acting barbiturate. It has to be mixed in water preceded by medication to prevent vomiting. This would produce loss of consciousness in a short time and death within an average of 30 minutes. The price of this medication has gone through the roof and is now more than \$3000.

In San Diego we had planned to follow the original Oregon model, now used by Washington, where we would help people to contact doctors and hospices, fill out the paperwork, work with families, and be there when the patient ingests the medication. Hemlock Society of San Diego has not yet decided whether to pursue the compassionate model. We hope Compassion & Choices is right and that people will be able to use the law easily on their own, but we get calls from people with MS, dementia, and other chronic conditions who would not be able to do so. We would prefer to direct these calls to FEN, but there are obstacles.

This is a difficult, restrictive, rather cumbersome law. We are struggling now with finding two doctors, cooperative hospices, and cheaper alternative medication. We are just at the beginning; hopefully we will be able to work together to help people what we promised—a peaceful, dignified death of their choice. ■



U.S.L.W.R.

Member Benefit:

U. S. Living Will Registration

Have you registered your living will? It is a benefit available at no charge to FEN members. It improves the likelihood that your end-of-life wishes will be known and followed.

The U.S. Living Will Registry (USLWR) is a secure, on-line database where you can store your advance directive and/or organ donor information. It currently stores more than 150,000 documents, 244 of which show membership in FEN which has been a partner since 2009. The document can be easily accessed by you, or any healthcare provider. It is completely confidential, like a medical record. Once registered, you will receive labels to affix to your insurance card and driver's license stating your advance directive is registered.

Take advantage of this program. The USLWR website currently charges \$59 per registration for unaffiliated individuals.

To receive this free benefit, request the U.S. Living Will Registry form by email at finalexitnetworkcontact@gmail.com, click the corresponding button on the member benefits page of the FEN website, or call the Final Exit Network number 866-654-9156. Once you complete the form, mail it along with your advance directive and/or organ donor information to:

According to the Registry's Gail Marner, "Often we receive calls from family members of people who are so very appreciative of our service. When a loved one is seriously ill, there is such a peace of mind that comes from knowing their wishes in advance. The burden is lifted off the family members and that is an invaluable comfort."

To learn more about the USLWR, visit www.uslivingwillregistry.com.

Good Endings Book Club



“Good Endings Book Club” is a compilation of reviews, ratings, and recommendations (and anti-recommendations) on books dealing with end-of-life issues. If you have read a thought-provoking book, or read a book you disliked, send your comments to hdevenzio@charter.net. The Club also welcomes debates and discussions among contributors.

The Ethics of Suicide by Margaret Battin

Review from Faye Girsh

Since her seminal work, *The Least Worst Death*, in 1994 Peggy Battin has been one of the most (arguably the most) prolific, thorough, gutsy writers on suicide and the right to die. To illustrate the breadth of her interests she recently co-authored, with Dr. Tim Quill, a paper for doctors on what to do when they have a request for assisted dying. Several years ago she and Ezekiel J. Emanuel conducted the classic study to determine what, if any, savings would be gained by permitting terminally ill patients the right to have physician-aid-in-dying (not very much, is their answer). Then there was another classic study she co-authored showing that there were more assisted deaths by doctors in jurisdictions where it was NOT legal than where it was legal. She has movingly argued that demented patients should have some way out before completely losing their personhood. She also got a lot of exposure (TED Talks, Terry Gross interview, etc.) when her professor-husband, who became a quadriplegic in a bike accident, chose to end his life.

Now, she has edited this massive work on suicide, *The Ethics of Suicide: Historical Sources*, which is a comprehensive collection of historical sources concerning issues in suicide. Oxford University Press

in partnership with J. Willard Marriot Library at the University of Utah (where she has held a distinguished professorship for decades) cooperated with her for an associated online Digital Archive. The work has already received Honorable Mention for the PROSE Award (American Publishers Awards for Professional and Scholarly Excellence), Category Philosophy, 2016.

This is not a work you might read on the beach. It is 700+ pages long and its content is enhanced by the references which the library provides. What she and her co-authors do is cite sources in classic literature, the Bible, tribal references, other countries, etc. For example, in discussing the cause of Indian Home Rule, an author makes an argument for self-destruction rather than killing others to achieve a justifiable end. There is also a piece on old people choosing suicide for the good of the tribe. There is no doubt that this is the most exhaustive exploration of suicide ever assembled and it removes the stigma of the act when it is the service of higher goals or eliminating human suffering.

The Good Death by Ann Neumann

Review from Ann Mandelstamm

With the appearance of *The Good Death: An Exploration of Dying in America*, author Ann Neumann, a visiting scholar at the Center for Religion and Media at New York University, has produced the book I always wished someone would write. It is intelligent, compassionate, fair, thorough, well-researched and graceful, in both meanings of the word. Before writing this book, she spent a great deal of time with her own father in his last illness and with many patients in hospice, volunteering with them throughout their dying process. She emerged with insights on the ways that religion both comforts the dying and makes their struggles more conflicted and less autonomous.

Most of all, she acknowledges that while medical care has added an additional thirty years to the average life span in the last 100 years, it has also often made death something we experience only from a distance rather than something that takes place in our homes. She says, “Death has been put off and professionalized to the point where we no longer have to dirty our hands with it.” Even the dy-

BOOKS continued on page 14

ing person may be protected from the truth. Most terminal patients are in hospice less than two weeks, hardly long enough to come to terms with the reality. She acknowledges that many don't "so much make decisions as drift into passive indecision and acquiescence to authority, whether it be that of doctors or nurses or a hospital board." And she also admits that not all hospices are what they should be. Her book is a call for all people to take seriously the one thing we are all certain to do – die.

The subject of this extraordinary book is heavy, but Neumann sprinkles it with delightful and touching stories of real people facing death, names changed, of course. She understands that this final stage of life can be acceptable, even empowering, if a person is lucky enough to experience "kindness, attention, and friendship of the human heart." What renders dying terrible is unbearable pain, confusion, and a sense of being abandoned. She advocates strongly for everyone to have the right to say how much suffering he or she is willing to endure.

The reader of this book will learn more about many newsworthy people: Terri Schiavo, Cody Curtis (the woman featured in the documentary *How To Die in Oregon*), John Rehm, even prisoners in Guantanamo on hunger strikes, inmates on death row and prisoners dying of illness or old age. She knows that for-profit health care in most prisons causes more suffering than it alleviates. Most books on dying skirt these stories. As well, Neumann helps the reader feel compassion for the disabled activists in *Not Dead Yet*, a group with whom the World Federation of Right-to-Die Societies and Final Exit Network had very trying experiences in their 2014 conference in Chicago. Virtually everyone in the death with dignity movement will learn much from this book that they never knew or considered.

Neumann openly admits that the good death may elude us, because "it always hurts, both the dying and the left behind. But there is a good enough death. It is possible to look it in the face, to know how it will come, to accept its inevitability. Knowing death makes facing it bearable. There are many kinds of good enough death, each specific to the person dying. As they wish, as best they can. And there is really one kind of bad death, characterized by the same bad facts: pain, denial, prolongation, loneliness."

It's OK To Die by Monica Williams-Murphy M.D. and Kristian Murphy

Review from Joan Patterson

A few months ago I attended a presentation by Dr. Monica Williams-Murphy, an ER doctor and the co-author of this relatively short and easy-to-read paperback book. Her presentation was excellent – measured, informative and concise – but her book was even more so. If you ever wanted to know what really goes on in emergency rooms, especially for those individuals who arrive there near the end of their lives, and what you don't want to go on, this is a book to read. And that's just the first section. The following four sections deal with issues such as how to refuse medical interventions (if you don't want them), practical information about good advanced planning, "Six Things That Must Be Said to Make it OK to Die," terminal illness, palliative care, dealing with the funeral industry monopoly, and other end-of-life decisions you might have to make.

I particularly liked the form that is included in the book (an adaptation of the PPS (Palliative Performance Scale) which lets you decide how you want to be treated if and when your health starts to decline.

The authors, in their Position Statement at the beginning of the book, say that they are not euthanasianists and that they do not support physician-assisted suicide. However, the final section of their book, titled "Politics and Death – Choosing Our Own Future and the Future of the Nation," argues forcibly and effectively for major changes to the healthcare system, including new policies that would facilitate better end-of-life processes and planning on the part of both the medical profession and patients. I couldn't agree more, and as Dr. Monica's husband and co-author writes in closing, there are three R's on which we can all agree: "REDUCE the suffering of the patient; REDUCE the suffering, depression, and stress of the family; and REDUCE the cost of unnecessary and unwanted medical treatment (and save the federal and state governments tens of billions of dollars!)." As a long-time member of Final Exit, I say "bravo" to these two authors for writing this great little book. ■

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