

SUPPORTING THE HUMAN RIGHT TO A DEATH WITH DIGNITY

**Renew your membership online:
www.finalexitnetwork.org**

This is the reaction of Rev. Susan M. Flanders to an article by Zach Fox, staff writer for GoUpstate.com, dated Jan. 4, 2018. Rev. Flanders is an Episcopal Priest in Washington, D.C., where she conducts programs on end-of-life issues and serves on the board of Progressive Christianity.

A “Mercy Killing” in South Carolina

By Rev. Susan M. Flanders

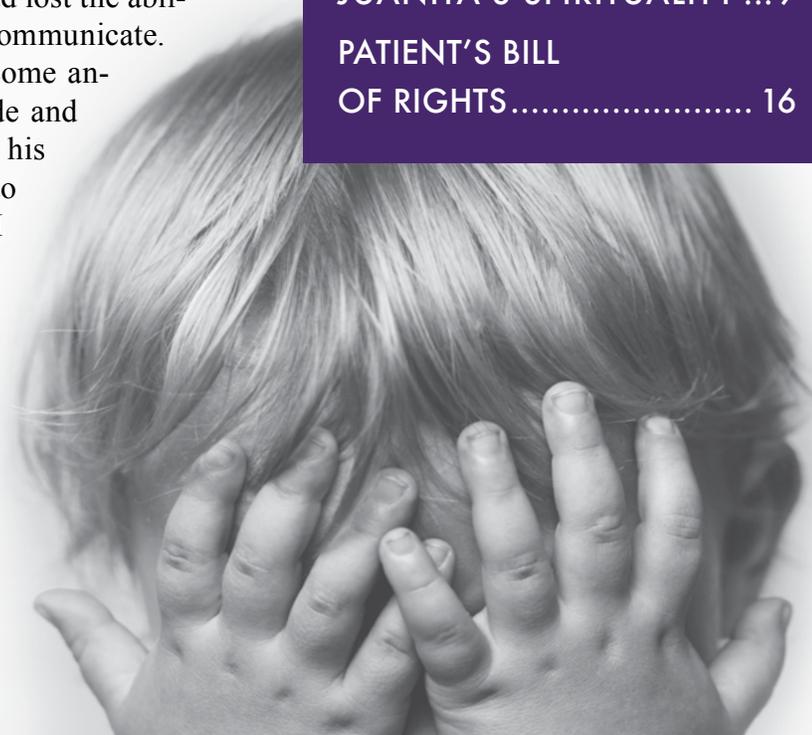
A story about a man shooting his parents to death gives a poignant account of the desperation of a couple who no longer wanted to go on living due to extreme illness and debilitation, and the dilemma posed to their son who cared for them.

The mother had suffered from strokes and had lost the ability to walk or care for herself and could barely communicate. The father had begun drinking heavily and become angry, violently abusive. He often talked of suicide and several times asked his son to shoot him and his wife. “I could not count the times he asked me to shoot him and momma,” David Belcher said. “I knew he was serious.” Finally, even his mother joined the plea, saying, “Son, do what your dad asked.” The son pled guilty to voluntary manslaughter to avoid a murder conviction and was sentenced to ten years in prison, despite his own and his siblings’ conviction that what he did was out of love, and a mercy at the request of his parents.

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This is a sad story, and there is so much about it that could have been different, had our laws and our cultural attitude towards end-of-life situations been different. First of all, one wonders about whether the mother, 69, could have had better care—whether in home or in hospice, and what prevented this. Did the family lack means to pay for such care, or did she insist on being at home with only her son to care for her and her husband? And surely the husband, only 69, could have gone on living and gotten help in addressing his addiction, rage, and probably depression, whether or not his wife was still alive.

But let's assume both parents considered their lives intolerable and no longer wanted to live. Did they have a right to request such "mercy" from their son, or should they have managed to end their lives themselves? What if the mother had written out explicit advance directives asking for aid-in-dying should she ever reach an extreme state of disability? Even if aid-in-dying was illegal in South Carolina, which it is, perhaps her directives could have included a desire to stop receiving food and liquids, or VSED. If the family, parents and all three children had talked about this directive and agreed to help their mother when the time came, perhaps she could have died in a non-violent way, but in

accordance with her clearly stated wishes. And perhaps, if the husband had been able to support his wife in honoring her directives, he maybe could have gotten his own life back on track and had a fairly good quality of life for some years.

It is saddening as well to consider the situation of the son, the one sibling apparently able to care for the parents and the stress of this responsibility. Can we imagine that he snapped one day, exhausted, overwhelmed, hating to see the misery of his parents? With repeated requests from his father to kill them, and then his mother's assent, can we see him picking up the gun as a last resort, a tortured, unnatural act of love? And then why did he go, covering the bodies with sheets, leaving them to be found ten days later—was he in shock, frozen with remorse or fear by what he had done?

I am certain this story is not unique, that others like it happen more frequently than we know. I ache for these families. Their last illnesses and deaths could be so much more humane and more dignified if we allowed relief through well-crafted aid-in-dying laws. ■

“Did they have a right to request such ‘mercy’ from their son, or should they have managed to end their lives themselves?”

No one should have to die a traumatic death due to their suffering –

And no one should be forced to die alone.

— *Final Exit Network*

Aid in

Dying

Should

be a

Decision

Made

by the

Patient

The following commentary was originally published
by the *Albany Times Union* (Capital Newspapers)
on April 28, 2018.

By William M. Brooks and David C. Leven

Medical aid in dying allows a physician to prescribe life-ending medications to a terminally ill patient—likely to die within six months at the patient’s request. The patient may then consume the medications if he or she decides to do so to end suffering and achieve a peaceful death. Some medical organizations have been opposed to this practice. However, many have reconsidered and now either support or are neutral on medical aid in dying as an end of life option. This is a very significant development.

Lawmakers should consider the changing attitudes of physicians and medical associations when reviewing New York’s Medical Aid in Dying Act, which provides numerous and adequate safeguards. The vast majority of dying patients do not choose medical aid in dying, as hospice and palliative care adequately relieve the suffering of most patients. However, the option should be available for those dying patients who have unbearable and uncontrollable suffering, in consultation with physicians and family members.

Respected medical organizations including the American Medical Women’s Medical Student Association have supported medical aid in dying for years. Others, including the American Academy of Hospice and Palliative Medicine, have remained neutral. To our knowledge, no major medical organizations have formed new positions against medical aid in dying in recent years. And it should be noted that physicians nationwide support medical aid in dying by an almost 2-to-1 margin, 57 percent to 29 percent, as do about three-quarters of New Yorkers.

In recent years about ten state or national medical associations have dropped their opposition to medical aid in dying, including those in Massachusetts and Vermont in 2017, and the American Academy of Neurology. These medical organizations will support the right of their physicians to engage in the process of medical aid in dying. This marked shift toward either endorsement or neutrality is very important as thinking about medical aid in dying evolves. And it is not surprising, given the extensive and overwhelming evidence that this has been an ethical and beneficial medical

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Should We Contribute Money to Cure Diseases?

By Huck DeVenzio

Though it seems charitable to humanity and beneficial to sufferers to contribute money to find a cure for cancer and kidney disease and other fatal diseases, I wonder if that is our best use of funds.

We are all going to die. If we get rid of one killer disease, won't another take its place? To think otherwise discounts human history and denies the inevitability of death. The possibility of immortality is unlikely, and if it is feasible, we should consider if it's desirable.

Wouldn't it be preferable to seek ways to improve life rather than avoid death? Not curing disease is contrary to our nature—we want to pursue longer life—but is this a warped priority? We should care more about how *well* we live than how *long*. ■

Right-to-Die Advocate Honored by Humanists

By Eric A. Gordon

The following was taken from an article, "Honored Humanists...", published by People's World (peoples-world.org) on May 25, 2018.

An organization such as the American Humanist Association is in the business of tracking the public figures who align with its values and, through the work they do, promote its vision. This year, as every year, at its 77th annual Conference AHA presented several awards to individuals who have furthered the cause of secular knowledge.

Science writer and advocate, Los Angeles-based Jennifer Ouellette became the newest AHA Humanist of the Year. Ouellette has written popular science books, and edited *The Best Online Science Writing 2012*. Her writing has also appeared in a number of print and internet magazines. She also holds a black belt in jujitsu!

The honoree took the podium stating she was going to speak from the heart. Many Humanists have progressive ideas about end-of-life issues. For them there is no grace or sanctity in prolonging life for life's sake against a person's will. At the Conference there was in fact a Final Exit Network booth distributing information about the choice to end a painful life.

Ouellette spoke about the painful last three months of her brother David, who had died three years earlier from a fast moving cancer. She wanted to speak about "how to have a good death at the end of a good life."

Her first point was that medical professionals have to be honest about a patient's diagnosis. It actively harms a patient to pretend there are cures or unknowable outcomes in hopeless cases. Patients have hard critical decisions to make on the basis of information they receive, and it must be accurate. Also, more resources and research must go into pain management. In David's case the pain was unbearably intense, but the professionals helping him could only commit to just "staying ahead" of it.

Right-to-die legislation needs to be passed in every state, and even where it is the law, there are formidable hoops to jump through. In California, where

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practice over three decades in Oregon and Washington and in several other states.

Medical aid in dying laws have worked, as facts demonstrate, as intended. Patients and family members benefit, and no harm is caused. None of the problems opponents expected have emerged. There has not been a rush by terminally ill people to end their lives; only about one in 300 dying patients access medical aid in dying, although thousands of dying patients are comforted knowing the option exists. There has been no disproportionate impact on vulnerable populations, no evidence of coercion or abuse, no slippery slope. There is evidence that those who die by medical aid in dying have at least as good if not better deaths than those who die by other means. Medical aid in dying laws have been implemented so well that there have been no serious or successful efforts to rescind or amend them in any significant way.

The Medical Society of the State of New York should adopt a neutral position. And the Medical Aid in Dying Act should be enacted into law. ■

People Shouldn't Suffer

A Tribute to Rosalie Guttman

By Huck DeVenzio

Rosalie didn't know how well her acceptance speech would be received. After all, she points out, death and self-deliverance are still taboo among many people. That did not stop her from extolling the efforts of Final Exit Network and the need for end-of-life choice. Apparently her logic and her charm, perhaps coupled with changing attitudes, won over her audience. After concluding her remarks, her son exclaimed, "Mom, you got so much applause!"

The occasion was a ceremony in April of the University of Illinois School of Public Health in which Rosalie Guttman was given an award for her years of service to gerontology. Her message was simple and seemingly indisputable: People shouldn't suffer.

Rosalie grew up in England during World War II and was exposed to much suffering. As a teenager she undertook volunteer work in a hospital. When she migrated to the U.S. in 1957, by herself, her experiences led her to study gerontology, eventually earning a Ph. D. She co-founded the Hemlock of Illinois and Final Exit Network, which she has served as a Board member, Advisory Board member, and an Exit Guide.

Now 85 and less able to travel, Rosalie is discontinuing her active role of public speaking—you can still see her debate the issues on YouTube—but not her dedication to FEN. "I have a Life membership, and needless suffering still makes no sense to me."

As an Exit Guide
and a former
Caring Friend,
Rosalie witnessed
about a dozen exits,
each one a moving
experience.



Most memorable to Rosalie have been the people she has met over the years, remarkable people with similar views and concerns.

As an Exit Guide and a former Caring Friend, Rosalie witnessed about a dozen exits, each one a moving experience. Two stand out. One involved a 90-year-old woman from a family of educated scientists. She had fractured her hip and rejected medical treatment saying, "I do not want to spend another day on this planet." Adoring family members convened from across the country on her birthday to be part of the exit. She died, surrounded by loved ones, to a recording of Schubert's Trout quintet.

The other exit was a much younger man with a different choice in music. A religious Catholic in his 50s, he had been a lifelong quadriplegic with limited feeling in one hand, which was fading. He thought it was time to

go and wanted to depart to the sound of a Buddhist chant. Surprising to Rosalie, her FEN associate knew the chant and was able to accommodate the request.

When Rosalie began her career, death with dignity was not a commonly used term. Asked about the future of the death-with-dignity movement, she admits that she does not know. But, in the long run, she is optimistic. She thinks the growing elderly population and greater willingness to talk about death are signs that there could be a time ahead when more agree that "People shouldn't suffer." ■

Excluding Psychoses from PAD Not Justified

By Rooney, W.; Schuklenk, U.; van de Vathorst, S.
Abstract from paper published in *Health Care Analysis*, June 17, 2017.

Are Concerns About Irremediableness, Vulnerability, or Competence Sufficient to Justify Excluding All Psychiatric Patients from Medical Aid in Dying?

Some jurisdictions that have decriminalized assisted dying (like Canada) exclude psychiatric patients on the grounds that their condition cannot be determined to be irremediable, that they are vulnerable and in need of protection, or that they cannot be determined to be competent. We review each of these claims and find that none have been sufficiently well-supported to justify the differential treatment psychiatric patients experience with respect to assisted dying. We find bans on psychiatric patients' access to this service amount to arbitrary discrimination. Proponents of banning the practice ignore or overlook alternatives to their proposal, like an assisted dying regime with additional safeguards. Some authors

have further criticized assisted dying for psychiatric patients by highlighting allegedly problematic practices in those countries which allow it. We address recent evidence from the Netherlands, showing that these problems are either misrepresented or have straightforward solutions. Even if one finds such evidence troubling despite our analysis, other jurisdictions need not adopt every feature of the Dutch system. ■

HUMANISTS *continued from page 4*

David was dying, the wait time exceeded his expected lifespan. His only recourse once he refused further treatment was to starve himself to death. "That should not be the fallback option," said Ouellette.

Finally, in their family, the issue of death was complicated by their parents' evangelical beliefs. They refused to admit he was going to die, would not have the difficult conversations the whole family needed, and delayed the acceptance process. To them, his death would only confirm his lack of faith in Jesus. Secular people in the family found it easier to deal with his death than the religious members.

"This all too short life is all we have," Ouellette says. "What is compassion? Prolonging someone's life or ending their suffering?" She cited the political battle society is fighting over the issue of death with dignity, and the religious community's unhelpful influence on legislation. Yet, she says, "Long-term, people do change their minds. First change their heart, and be patient. Keep doing what you're doing, and change will happen." ■

Did You Know?

People over the age of 70-1/2 years are required to take a minimum distribution from their retirement investments each year. These are pretax dollars that have been growing over the years. By merely instructing the investment company to make a distribution directly to FEN, the individual can continue to make a tax-free donation in any amount at any time of year. Check with your financial advisor for confirmation.

Information you may need: Our EIN #80-0119137 and address, Final Exit Network, P.O. Box 10071, Tallahassee, FL 32302.

Our thanks to Board member Gary Wederspahn for this tip. ■

Exit Services Necessarily Withheld

By Janis Landis

Recently, a FEN member expressed disappointment at not qualifying for Guides Services. In responding to their understandable frustration, I sought to emphasize that there are complex factors that must go into our decision. Membership in FEN is a way of supporting our advocacy of end-of-life autonomy; it is not a guarantee of acceptance into our Guides Services program. It might be helpful to share part of that letter to help explain two of the major non-medical issues that impact our analysis:

I know that you are suffering greatly, that you have availed yourself of every type of medical intervention that could possibly help, and that despite this, your quality of life has been severely impacted. And yes, you have met a significant portion of the criteria for receiving Guide Services. So I understand your frustration and disappointment at being turned down.

But, with respect, I think your anger is misdirected. From my way of thinking, your anger should be directed at those in elected office who refuse to enact laws that implement the clearly expressed will of Americans for autonomy in life decisions. It should be directed at judges who deny us our Constitutional right to make those decisions. It should be directed at State District Attorneys who make a great publicity coup out of prosecuting individuals for providing information to those seeking to end their suffering. It should be directed at psychiatrists who refuse to acknowledge that sometimes there is nothing more that can be done to relieve their patient's

suffering, and then use the resulting despair as further evidence of the patient's inability to make self-determination decisions.

FEN's mission is to address these injustices. Doing this entails great physical and emotional stress. It exposes us to legal and financial devastation. But we persevere out of a sense of commitment.

At the same time, we have a commitment to our organization to not put it in jeopardy by taking risks that would shut us down. And we have a commitment to our families to not take risks that would put us in jail.

Our legal advisors as well as our own experience with prosecutors have made it clear that there are two types of cases that expose FEN, and us personally, to the greatest risk.

The first of these is lack of family awareness of the individual's intent. In every single prosecution we have faced, it was aggrieved family members who had not been informed in advance of the plan who insisted that charges be brought against our Guides. Their testimony, while it is (from my point of view) hypocritical and self-serving, nevertheless has a powerful effect on district attorneys, juries, and the public.

Mental illness presents a different but equally difficult barrier for us. Family members, doctors, etc. will come forward and say that it was suicide. Psychiatric experts will testify that there were plenty of other options for treatment, that we took advantage of an individual of unsound mind and we will be convicted of assisting in that suicide. In fact, a very similar scenario occurred a few

MENTAL ILLNESS *continued on page 15*



Walking Her Dog



Eddie Got a Shiner



Butterfly Dress



Juanita Ainsley 2012

JUANITA AINSLEY

Juanita's Spirituality

Rev. Kevin Bradley

Juanita Ainsley's death in May generated this response from a Board member. Juanita was an accomplished artist and a staunch advocate of death with dignity and FEN.

I met Juanita during exit guide training in 2016. Shortly after the training, she asked me to serve as an associate guide for a client who requested spiritual support. The situation required us to stay in the client's area for two days, during which time I learned a bit about Juanita's career as a psychologist, her sons, her art, and of course her passion for FEN. I felt privileged to be given a glimpse into her remarkable life. A while later, she asked if I could providing spiritual counseling for another client over the phone even if I didn't act in a guide capacity. The client was so grateful that Juanita then recommended my services to all guides, and I soon found myself having phone consultations with clients across the country. Those phone consultations have also indirectly led to the board considering developing post-exit debriefings to guides, both as emotional/spiritual support and as a means for continual improvement of our guide program.

Juanita's stated reason for inviting me to go on that first exit trip with her was that she didn't feel "qualified to provide spiritual guidance." I can't help but smile at that comment now. Maybe she didn't have the vocabulary to be comfortable discussing certain religions, but I think living a spiritual life is ultimately about service and being fully present, the combination of which in turn requires equal parts grace, courage, and humility. Juanita clearly lived a life of service, and anyone who knew her would say she was fully present. I am optimistic that her suggestion to offer spiritual support to clients and guides will lead to an even stronger guide program. It is difficult to imagine a greater legacy.

I don't think I've ever known anyone more "spiritual" on so many levels. ■



WHY I WORK FOR FINAL EXIT

By Eleanor Aronstein, *Affiliate Leader in upstate New York*

No one really enjoys thinking or talking about death, but sometimes we're confronted with a situation in which we have no choice. Such was my introduction to death—many years ago.

My beloved mother was diagnosed with ovarian cancer in 1971. At the time, she lived in Florida and I lived with my husband and three little boys in New York State. Over the course of the next eleven months, I flew to Florida for four- or five-day visits, sat at her hospital bed, offered murmurs of denial and protestations of love. Conversations with her physician never approached reality because I didn't have the emotional strength and vocabulary to realistically deal with the situation. There were sentiments that should have been articulated, words of love and gratitude that should have been voiced. But they weren't. The final months must have been torture for my mother, yet I never heard her complain. She bore each medical assault with grace and hope—or was it resignation? I'll never know. And, yes, I feel guilty!

“Conversations with her physician never approached reality because I didn't have the emotional strength and vocabulary to realistically deal with the situation.”

When our beloved Golden Retriever was very elderly and infirm, I took her to the veterinarian, who injected her with a barbiturate while I cradled her in my arms and sobbed uncontrollably. Princess had a peaceful death. How I wished that my wonderful mother could have died like a dog—cradled and comforted as a barbiturate ended her suffering.

Today I am a supporter of both Final Exit Network and Compassion & Choices; I believe in a

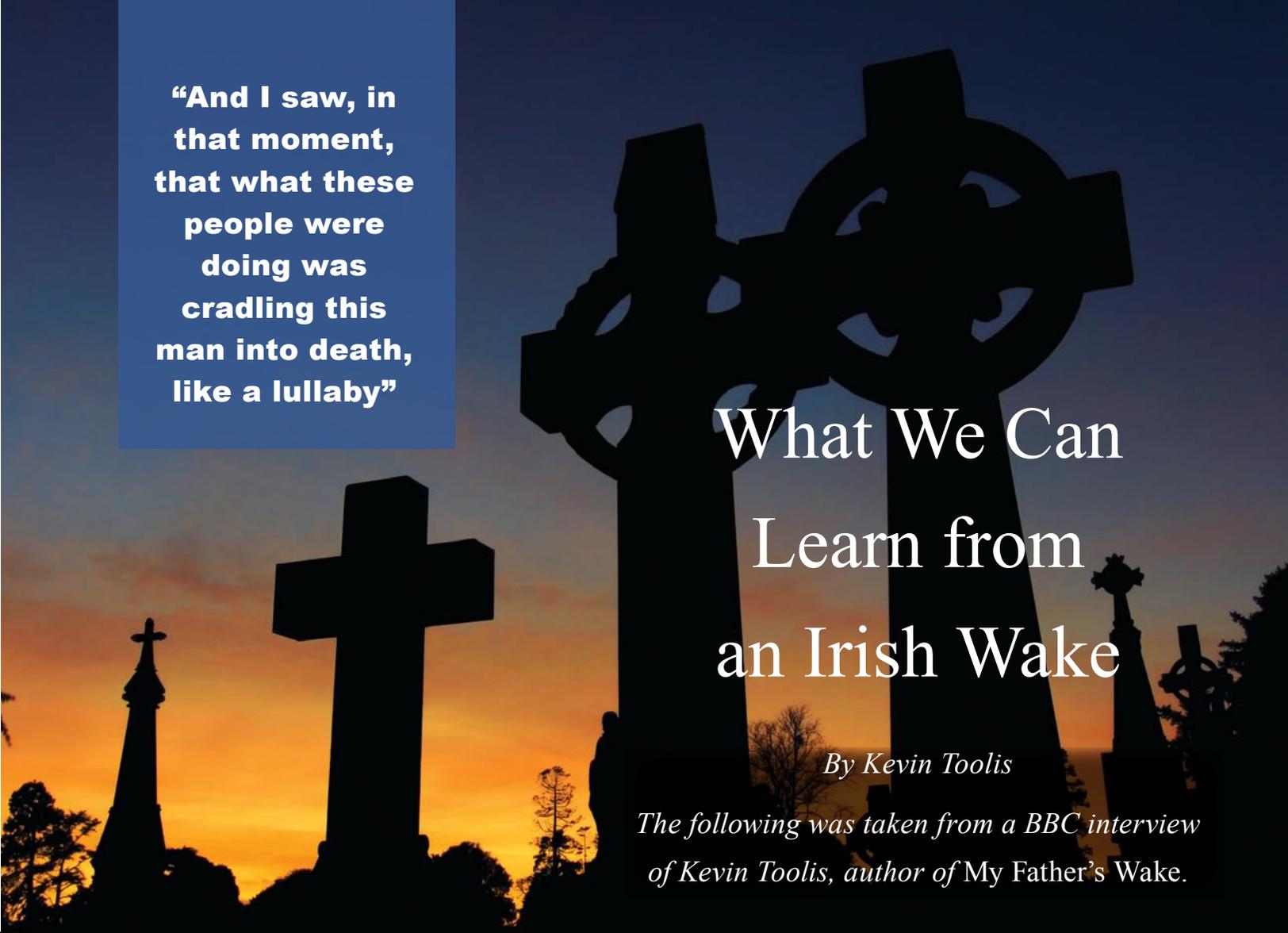
person's right to self-deliverance and I believe in legalization of Physician Aid in Dying. They go hand-in-hand.

So how did I become an activist? My husband and I moved upstate to Schenectady in 2013 and I decided to put some muscle behind my longtime but passive support for the movement. I truly do not recall how I was put in touch with Hedi McKinley but it was probably through FEN officers. Hedi came to my home with bags of information/materials/handouts. She was 93 years old at that time and a dynamo! There were other women who were supportive and helpful and encouraging. Martha Schroeder and Nicole Sharpe educated me, and we launched a Final Exit Network Upstate NY Affiliate. It was truly a group effort.

As a retired History teacher (high school and college), speaking in front of groups was no problem. We reserved the library nearby and put an ad in the local paper. My husband Jesse helped with the technical problems as I put together a PowerPoint presentation. We printed hundreds of flyers and distributed them....and Voila! At our first public program, we had standing room only! We had hoped for forty or so people and we had close to eighty! Yes, we got several to sign up and join Final Exit.

In the intervening years, I've done many programs in the area. I will travel to any venue. My husband always accompanies me and we joke that he is my “roadie” in this endeavor. I always start my program by asking how many people expect to leave this earth alive. Haven't had a hand raised yet! It's my tribute to my mother—her photograph graces my first slide. Princess is there, too, when I make the point that it would be more humane to let people die like a dog rather than endure needless suffering.

Society evolves. It's time for the ultimate right—control over the terms of one's own death. This is truly the final civil right. ■



“And I saw, in that moment, that what these people were doing was cradling this man into death, like a lullaby”

What We Can Learn from an Irish Wake

By Kevin Toolis

The following was taken from a BBC interview of Kevin Toolis, author of My Father's Wake.

If you've never been to an Irish wake and have only seen the movie version, you probably think it's just another Irish piss-off, with a few people around a coffin drinking pints of Guinness. But you would be very wrong.

In my father's island off the coast of Mayo, people go to wakes of their neighbors. They see dead bodies, they touch dead bodies. They take children to those wakes. So even an ordinary person, away from the medical profession, would see 20, 30, 50, sometimes 100 dead bodies. My father didn't want to die—he was only 70—he was a powerful, physically fit man. But then he got pancreatic cancer, and pancreatic cancer is one of those cancers that no one ever recovers from. He was quite stoic about it. And more importantly, his community accepted his fate. It came to

see him in the dying process. The house filled with visitors, so many visitors that you actually thought the house was celebrating a wedding feast. I was at the foot of my father's deathbed, and I looked around. There were twelve people in the room, some of whom I didn't know.

And at that moment the Chief Keener [wailer] struck up a very familiar Catholic prayer of the five sorrowful mysteries. *Holy Mary, Mother of God, pray for us sinners now and at the hour of our death.* And then the chorus returned the other chant. *Holy Mary, Mother of God, pray for us sinners now at the hour of our death.* When the chorus said that second verse, that sound grew louder and louder and louder in that room until it was almost the loudest sound I had ever heard in my life. And I saw, in that moment, that what

IRISH WAKE *continued on page 12*

IRISH WAKE *continued from page 11*

these people were doing was cradling this man into death, like a lullaby.

This scene was not a Western hospital, but a right within an Irish clan. A way of dealing with death that probably was as old as the fall of Troy. A mechanism by which people could share their death, share this experience, learn about their own deaths. And also share this, normalize this within their community.

Later the same day my dead father was taken. He was placed in a coffin and just moved a few feet away into the front sitting room and there we had a full, old-fashioned Irish wake. The women came and controlled the stage of the wake, the emotional temperature, whether they cried or keened. When a new mourner came in there was a new wave of emotion. There was a ripple through the room. It was a process by which you drained out emotion, where you moved on to the stages of acceptance of the death. And then we waked with my father the whole night through. During this wake, as well, there were lots of children around. There were three-year-olds and five-year-olds playing at the feet of the coffin. The house was full of people talking, feasting, being served tea and sandwiches.

Another thing about the Irish wake is that people come in great numbers to the funeral. So my father, although he was a very ordinary man, had three or four hundred people come to his funeral. And they were also under a moral obligation to shake the hands of the principal bereaved. It wasn't enough just for them to be there in the crowd; they all came up to you and shook your hand as they said "Sorry for your trouble." In fact they shake your hand so many times, the bones in your hand begin to ache. This is a way of couching death in Ireland. These individuals shaking your hands are saying not only "Sorry for your trouble," but "they're dead, they're dead, they're dead, they're dead." At the end of that existential experience it's hard to think they're coming back, which is a normal grief reaction.

I think the best way to deal with death is not to invent a new ritual or appoint another priest caste or bereavement counselors or medical professionals; it's to do what we've always done and that's to gather together as fellow mortals in the face of our mortality.

No Dignity in Life ... Or Death

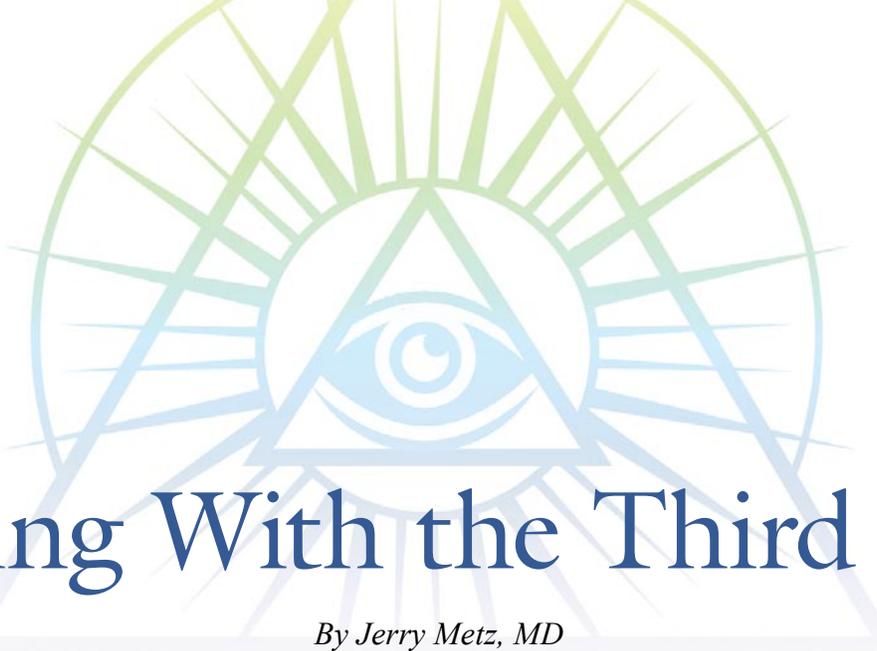
By Janis Landis

A highly respected Professor of Ecology in Australia has managed to infuriate the powers that be in Australia, twice.

Two years ago, at the age of 102, Professor David Goodall drew the disfavor of officials at Edith Cowan University in Perth for his insistence on coming to work. Professor Goodall knew his limitations; he was no longer teaching or researching, but he went on to the campus to be part of its academic life and to keep his mind and body active. This was too much for the University officials who decided that his advanced age made him a safety hazard and summarily banned him. Evidently the dignity of old age was not a value there. Public outrage over news of the banning forced a hasty and ungraceful retreat by the university (the familiar "sorry, not sorry" apology).

Then, the Professor made himself a pariah again. Having been pretty much told that he had lived beyond his expiration date, he decided, at the age of 104, he had completed his life and wished to end it on his terms. Unable to do this legally in Australia, he traveled to Switzerland where physician-assisted dying is accepted. He died by injection of a doctor-prescribed drug while listening to Beethoven's Ode to Joy. Professor Goodall had plenty of international support via social media, but, not surprisingly, Australian officials are once again aghast! All life has dignity they say. No one should end their life prematurely.

It would be hard for me to make up a story that better illustrates the hypocrisy of societal attitudes: no longer treated with dignity because of his age, but not allowed to end his life with dignity, despite his age. ■



Seeing With the Third Eye

By Jerry Metz, MD

A long time ago in a galaxy far away I was a young assistant resident in surgery. In medical school I had learned about the construction of the human machine and what made it tick. Now I was learning how to fix it when it broke. Hip fracture called for the pounding in of the newly-developed Smith-Peterson nail. Repeated ear infections in a kid justified the scraping out of tonsils and adenoids. As for cancer, “when in doubt, cut it out!” We were sharp then, mentally and manually, and there was an operation to correct every malfunction.

I was writing orders at the nurses’ station one morning when a commotion erupted halfway down the hall. I had no patients on that corri-

dor so normally I would have ignored the din, but this volume of noise would have attracted the attention of the nearly-deaf. The melody consisted of screams of terror in a male vocal register with a counterpoint of nurses in the soprano frantically calling the EENT resident and the attending nose and throat surgeon to come to Four West on the double!

Writing orders was boring so I strolled toward the noise hoping to learn something. What I learned opened a third eye that has not slept since.

The patient was a middle-aged male who looked strong and healthy except for the torrent of blood spraying out of his mouth at a rate I would have thought impossible. He was gargling it, choking on it, screaming past it in fear, eyes wide, trembling.

Throat cancer had abruptly eroded into a major vessel in his neck. When the Chief Resident arrived I saw his dismay as he began to calculate what kind of force it would take to win this battle, and I remember the expression of relief on his face when the Attending arrived and in his turn took on the mask of dismay. They attempted to cram sponges down the patient’s throat in an effort to tamponade the flood. They called the blood bank, they alerted the OR, but they must have known the war was lost.

As my third eye opened it saw clearly that a merely mechanical approach to a medical problem, skilled and high-tech as it may be, can be defeated by a superior enemy. More than that, it saw the entire picture:

two mechanics were pushing and patching a throat that was connected to a brain that was in ultra-panic mode. Here was a man seeing his life blood making a messy departure, well aware that he was about to die. Which he did. And they ignored him.

We cannot defeat death. We can stave it off, buy time, but we can’t banish it. And death can sometimes pounce in ways that are cruel. In seeing that man die I saw that, though we may not win the whole battle, there is usually a way to clip the claws of ugly death. If I had known then what I know now I would have sprinted upstairs to the anesthesia department and swiped one of their big syringes loaded with Pentothal and injected enough into the patient’s IV to

“Here was a man seeing his life blood making a messy departure, well aware that he was about to die. Which he did.”

THIRD EYE *continued on page 15*

Good Endings Book Club



With the End in Mind: Dying, Death, and Wisdom in an Age of Denial by Kathryn Mannix

Reviewed by Jim Van Buskirk

Kathryn Mannix is a “physician specializing in palliative care and a cognitive behavior therapist” in the United Kingdom. As such she is well-positioned to share stories from the “front,” i.e. deathbeds of those to whom she is ministering.

Generously sharing her decades of experience and expertise, she offers three dozen personal, poignant, powerful stories of how it’s done, whether well or poorly. Straightforwardly presented, and seemingly simple, they offer windows into worlds we might not know about, or want to visit. Whether the dying is a pet, patient, family member, or friend, Mannix gently, but persuasively, reminds us it is important to allow the leave-taking to be respectful and dignified. To initiate or facilitate the important if uncomfortable conversation, Mannix offers a letter template suggesting ways to begin, while her short glossary of important terms may or may not correspond to the American counterparts.

She believes that “reclaiming the language of illness of dying enables us to have simple, unambiguous conversations about death.”

End Game (Netflix)

Reviewed by Jim Van Buskirk

This touching, compelling, and important documentary by Rob Epstein and Jeffrey Friedman (*Howl*, *The Celluloid Closet*, *Common Threads*) is a change of pace for the award-winning directors based in San

Francisco. The short film follows several patients as they deal with difficult end-of-life decisions, offering a rare glimpse into the intimate conversations that are usually private.

With remarkable access to doctors’ offices and bedsides as well as waiting rooms and hallways, where challenging decisions and interpersonal dynamics play out, we meet hospice volunteers, nurses, physicians empathetically helping patients and their families deal with the reality of death. Foregrounded is B.J. Miler, the charismatic hospice and palliative care specialist at University of California San Francisco Medical Center, and the Zen Hospice Project, as he gently facilitates questions to which the answers are unknown. The final scenes reveal that Mitra dies at UCSF surrounded by her family, Pat and Bruce die at the Zen Hospice Guest House, Kym and Thekla at home.

Filled with laughter and tears, sweetness and sadness, this equally heartbreaking and heartwarming film ends with an important sound bite: “death is a part of life.”

My Father’s Wake by Kevin Toolis

Reviewed by Huck DeVenzio

Warning: This book is not light reading.

Irish author Toolis, a journalist and film-maker, gives greatest attention to his father’s death but presents an unrelenting parade of deaths—his mother, brother, Middle East combatants, Africans with AIDS—interrupted sporadically by his musings on death. He’s a detailed observer and a descriptive writer.

He makes no mention of self-deliverance, although he writes, “Now, as his son, I wanted [my father] to die, his end to be, and pressed the button on his morphine pump to release more of the drug into his bloodstream to make sure.”

Toolis says, “Death is a whisper in the Anglo-Saxon world...How can it be possible to never talk out loud about death in a world where everyone dies?” A fan of Irish acceptance of death, he offers advice to westerners in a concluding chapter titled “How to Love, Live and Die:” Go to an Irish wake. Take your kids along. Touch a corpse. Call a dying uncle. Visit the sick. Keep a vigil for a dying friend or relative. Be a pallbearer. If you’re dying, talk about it.

It’s interesting reading, but don’t expect any grins. (An interview with Kevin Toolis appears on page 11.)”

My Own Country by Dr. Abraham Verghese

Reviewed by Lowrey Brown

This book was published in 1994. Verghese was a young doctor and an infectious disease specialist when he joined the staff at a hospital in eastern Tennessee in the mid-1980s. *My Own Country* is his memoir of the AIDS epidemic in those terrifying, early years, when the disease first started appearing in his small community, so unlike the traditional big-city epicenters of the AIDS story in America. Verghese witnesses the nightmare of insane medical intervention, long past when even the devil would have called for mercy and finds himself wondering why he is so unprepared to help his patients once there is no more he can medically do. It is anything but a memoir of dignified death, quite the opposite, but I offer it here because it is a stirring tale of stigma, of silence, of strained relationships, and of death ... unbidden and unprepared for, burdened with all the judgments that we humans seem so quick to make. Society may have taken significant steps forward since then, but in some ways, we don't seem to have learned a damn thing. ■

THIRD EYE *continued from page 13*

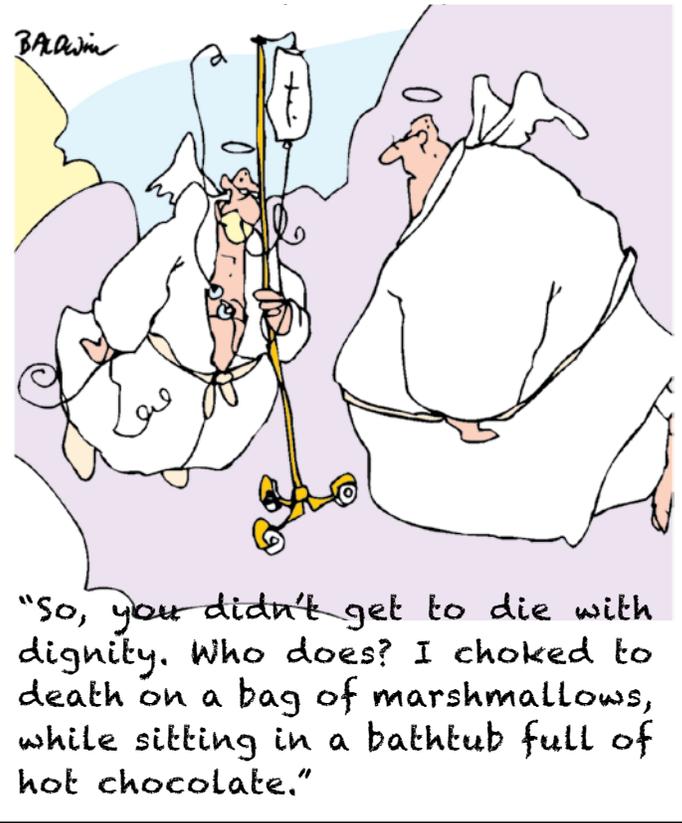
bring him peaceful resignation and help for the foot soldiers in their efforts to win a lost cause.

We medical people are better than we were a half century ago, better at treating the whole patient. Surgeons still get excited over the latest gadgets, the newest toys, but we're getting better at realizing that the fractured hip belongs to somebody's mother and the kid with tonsillitis is scared. We have come to accept the work of Hospice and even embraced the specialty of palliative care. We know all our patients will eventually die and that we will join them but we know that the natural and inevitable process of passing on should not be accompanied by screams of pain or stark terror.

We can defeat the occasional ugliness of dying, and that is an end so sacred I believe it justifies whatever means are required to secure it. It certainly justifies the dedicated efforts of our cadre of committed volunteers, the people who work for Final Exit Network. ■

Summer Newsletter, July/August 2018

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MENTAL ILLNESS *continued from page 7*

years ago and we were criminally prosecuted. While we ultimately did not get convicted of a felony, two of our volunteers were subjected to a long ordeal and ultimately decided to plead guilty to a misdemeanor in order to put an end to the emotional turmoil they were experiencing.

Because of these prosecutions, we changed our criteria a few years ago. The current medical criteria are clearly described on our website and more case-specific detail is provided after an individual contacts us. So the purpose we serve is clearly defined and Guides are able to provide information and a compassionate presence in the many cases that do meet our criteria.

Is it hypocritical of us to refuse to take further exceptional risks? Would it be better to take the risk and then be shut down and be unable to help anyone else? We do the best we can within the parameters of the law to provide compassion to those physically suffering while safeguarding our most important asset, the Guides.

No, we cannot help everyone who deserves help. We will do what we can until the right to self-determination becomes the law. ■

Final Exit Network • www.finalexitnetwork.org 15

SHARE WITH YOUR FAMILY AND YOUR DOCTOR . . .

THE DYING PATIENT'S BILL OF RIGHTS

BY JOHN ABRAHAM

I have the right to be treated as a living human being until I die.

I have the right to maintain a sense of hopefulness pertaining to how I will live my remaining days and my death, however changing its focus may be.

I have the right to be cared for by those who can maintain a sense of hopefulness, however challenging this might be.

I have the right to express my feelings and emotions about my approaching death in my own way.

I have the right to participate in decisions involving my care.

I have the right to expect continuing medical and nursing attention, even though "cure" goals must be changed to "comfort" goals.

I have the right not to die alone and to die in the place I wish.

I have the right to be free from pain.

I have the right to have my questions answered honestly.

I have the right not to be deceived.

I have the right to have help from and for my family in accepting my death.

I have the right to die in peace and dignity.

I have the right to retain my individuality and not be judged for my decisions, which may be contrary to the beliefs of others. ■

FINAL EXIT NETWORK
P.O. BOX 10071
TALLAHASSEE, FL 32302

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Huck DeVenzio, Editor
Julia Hanway, MA,
Layout & Design
Artwork originated from
Dreamstime.com

Final Exit Network, Inc.
PO Box 10071, Tallahassee 32302
QUESTIONS? Toll-free: (866) 654-9156

www.finalexitnetwork.org