

# FINALEXIT™ NETWORK NEWSLETTER

VOL 17 • NO 2

SPRING, MAY/JUNE 2018

SUPPORTING THE HUMAN RIGHT TO A DEATH WITH DIGNITY

[www.finalexitnetwork.org](http://www.finalexitnetwork.org)

## Dying in the Americas 2018 Conference Is a Winner!

**I**t was, by nearly every measure and every account, a great success. Typical was this unsolicited remark from a participant, “I was so inspired by the speakers and the attendees. The conference content was delightfully jam-packed, speakers were so interesting, evening events were connecting...”

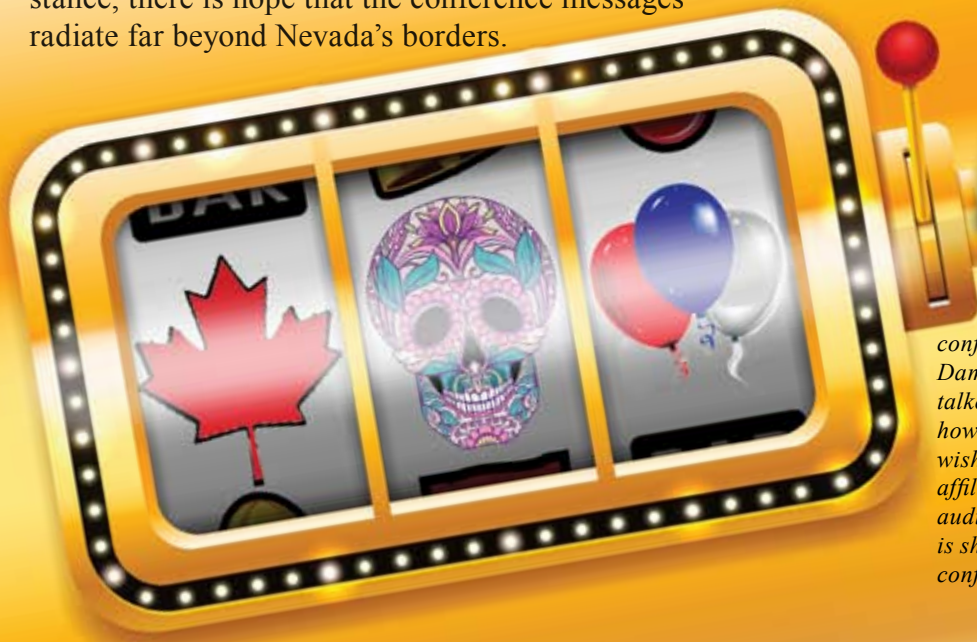
Sponsored and conducted by Final Exit Network, the “Dying in the Americas 2018” conference brought together about 150 activists, academicians, and interested people, along with YouTube’s favorite mortician, a rapping physician, and Canadian right-to-die revolutionaries for 3-1/2 days in an outskirt of Las Vegas. Attendees were informed, entertained, and motivated by a line-up of stellar speakers.

In this issue of the newsletter we present impressions of the conference—not summaries of all talks or highlights of the program, just a collection of impressions.

They say what happens in Vegas stays in Vegas. In this instance, there is hope that the conference messages radiate far beyond Nevada’s borders.

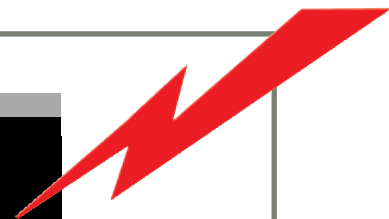


*Canada, Latin America, and the U.S. were represented in the hemisphere-wide conference. Friday Keynote Speaker, Dr. Zubin Damania (top), also known as rap artist ZdoggMD, talked about “Healthcare 3.0,” and a new vision of how healthcare can be more responsive to patient’s wishes. Above center, John Abraham (Arizona FEN affiliate leader) took part in one of many robust audience conversations. Bottom photo, Dr. Damania is shown with assistant Tom Hinueber and FEN conference coordinator Julia Hanway.*



## The Conference in a Flash

(3-1/2 days in 3-1/2 hundred words)



**A**fter **Faye Girsh** presented the historical evolution of Final Exit Network, a contingent of Canadians described how the Medical Aid in Dying idea became law in their country. **Shanaaz Gokool** warned that gaining and maintaining human rights takes never-ending effort and that “Judges read newspapers.” **Dr. Stephanie Green** discussed the Canadian law and cited some vivid case studies... **Dr. Asunción Alvarez** took us southward in outlining RTD laws in Central and South America, with emphasis on Mexico... **Ruth** “Control your life span; cut out the fat” **von Fuchs** and **Jurgen Dankworth** gave us another look at Canada... **Dr. Mara Buchbinder** showed us that doctor-patient communications can be beneficial but also can be harmful... We enjoyed popcorn with a movie... **Mike Morse** read a touching letter by **Barry Sinrod** on the toll of Alzheimer’s on a caregiver, and **Maia Calloway** read her own letter... Rapper and medicine man, **Dr. Zubin Damania (ZDoggMD)**, inserted a hip-hop perspective... A panel of insightful people including **Brian Ruder**, **Peg Sandeen**, and **Sally McLaughlin** related exit stories and talked about challenges nationally and in Washington state specifically... Spiritual goodness was spread by **Rev. Kevin Bradley** and **Gary Wederspahn**... Making your wishes known to medical professional was covered, in various ways, by **Dr. Carlo Reyes (POLST)**, **Dr. Aroop Mangalik** (“Be a bad patient; ask questions”), and **Dr. Richard Stuart (MOELI)**... We looked at death cartoons... **Thaddeus Pope** did not neglect the oft-neglected method of VSED... In an interesting panel (actually, they were all interesting), **Dr. Charles Gessert** opined on taming the end of life, while **Dr. James Downar** offered “The single biggest problem with communications is the illusion that it has happened.”... Internet personality **Caitlin Doughty** expressed the enlightened views of a young mortuary owner... **John Abraham** led a workshop on patient advocacy... **Robert Rivas** urged his audience to report instances where advance directives have been ignored and **Dr. Taimie Bryant** listed three areas of legal hope in the future... We sat at tables and had to come up with solutions. ■

**Thank you** to the many volunteers who made the conference so much more fun and engaging: FEN leadership, President **Janis Landis**, ad hoc committee members **Faye Girsh** and **Linda Banez**; indispensable onsite volunteers **Bill Schoolman**, **Glenna Cook**, **McKitterick**, **Holly McKinnis**, **Kristen Jochum**, students from NE Illinois University, FEN consultant **Heike Sanford**; as well as videographer **Kenneth Watson** and FEN member **Denie Aaron**, among many, many others who were all such a joy to work with and added so much to the event.



# Contemplating Mortality South of the Border

By Gary Wiederspahn

**W**hen I first traveled to Mexico in 1958, I experienced Mexicans gathering for a night-long vigil over the graves of their loved ones. This Noche de Muertos is an integral part of the annual Day of the Dead celebration. It involves cleaning and decorating the grave sites, bringing and sharing the favorite food and drink of the deceased relatives. The entire extended family is expected to participate. This festive event, full of music and laughter, is at the same time respectful and contemplative. It is a special time for the living to commune with the dead and to contemplate their own mortality. Children can even be seen happily eating candy skulls with their names written on them.

Anthropologists have seen this acceptance of death as a natural part of life, a characteristic aspect of Mexican cultural identity. I encountered similar customs while living in Colombia, Ecuador, and Guatemala. Day of the Dead festivals are common throughout Latin America and the Caribbean. So I was surprised to learn, at the recent Dying in the Americas 2018 conference, that our neighbors to the South face many of the same end-of-life issues and challenges that we do here in the United States.

Dr. Asunción Álvarez del Río is a bioethics and psychology professor and researcher at the medical school of the National Autonomous University of Mexico. She made an eye-opening presentation, "In Search of a Better Death—Achievements and Challenges in Mexico and Latin America." As author

**LATIN AMERICA** *continued on page 4*



## Conference Eavesdropping

*"Don't give up; if it were easy, someone would have done it by now."*

*"Most suicides in Oregon are attributed to loss of control, not pain."*

*"In Oregon, a state which allows medically assisted death, there are two times more suicides by VSED than by MAiD."*

*"Everybody has a say in my life but me."*

*"We have to infiltrate the Alzheimer's association."*

*"Do you believe that life is a gift from God or just a loan."*

*"All you need is one friend, one adult who believes in you, and one thing you can do well."*

*"The official flower of the radiologist: the hedge."*

Thank you to **Dr. Charles Gessert** for his fun and inspired collection of death & dying cartoons that he shared with conference attendees as part of the Friday night entertainment.

## Nuggets from Gessert

Dr. Charles Gessert offered these thoughts

*"When it comes to death, nearly everyone is an amateur."*

*"We have tamed childbirth, making it less painful, less dangerous, less uncontrolled, and less unpredictable. Now we're trying to tame the other end of life, making it less painful, less dangerous, less uncontrolled, and less unpredictable."*

*"The most important step in an advance directive is naming a surrogate."*

*"I'm honored to be here with the Enemies of Suffering." - Dr. Zubin Damania*

## LATIN AMERICA continued from page 3

and editor of groundbreaking books and articles on euthanasia and medical aid in dying, she is a leading spokesperson in the Americas. Her participation helped make the conference a truly hemispheric gathering. She reported on the Death with Dignity movements in Colombia, Uruguay, Chile, Panama, Argentina, Brazil, and Mexico. Colombia has achieved the most. There is some progress in the others but little throughout the rest of Latin America.

It seems that many of the same trends that have led to difficulty in achieving a good death in the United States are having significant impact in Latin America. Increasingly, the dying process has been institutionalized and professionalized. For example, the majority of Mexicans now die in a medical environment rather than at home. Consequently, the role of the family is reduced. In addition, the Day of the Dead has been commercialized and secularized, which has diminished its traditional reflective spiritual benefit. Furthermore, resistance to the right to end life on one's own terms is still very strong on the part of the Catholic Church as well as

among the rapidly growing evangelical groups.

Nevertheless, there are signs of hope and reasons for optimism. Dr. Álvarez highlighted the results of a 2016 public opinion survey in Mexico showing that almost 70% of the population agrees that terminal patients should be able to decide to hasten their deaths. Even more encouraging, nearly 70% of Catholics agree. With the people ahead of the policy makers, long-term prospects for Death with Dignity seem good. In 2016 Dr. Álvarez co-authored *A Farewell in Harmony: An Invitation to Accept Death and Embrace Life* to help educate and motivate the public. This non-academic book is reader friendly and covers acceptance of one's mortality, moral implications of end-of-life choice, and documenting and sharing one's wishes. Hopefully, at our next conference there will be more progress to report.

In the words of Spanish philosopher, Miguel De Unamuno: "Science says 'We must live' and searches for ways to prolong, facilitate, and amplify life...wisdom says 'We must die' and searches for a way to die well." ■



# Shanaaz Gokool Strikes a Chord

By John Abraham

**M**s. Shanaaz Gokool, CEO of Dying With Dignity Canada, and her compatriot, Dr. Stefanie Green, spoke with eloquence several times at our conference. It was Shanaaz's opening remarks that moved me most. She gave an impassioned and inspiring speech.

She told us about the makeup and history of the organization (37 years of championing this human right), told some sad case stories about those who ended their lives before the law allowed aid, and explained very well DWDC's focus on the individual, the person.

She received a standing ovation, and I think I was the first one to rise.

Some excerpts:

*"When I was thinking about my remarks for this evening, I thought of an interview I had with a Macleans magazine reporter last summer. We were talking about the poor rates for clinician compensation for assisted dying in BC. She was very curious why we were advocating for a fair fee structure. For us the answer is simple, we advocate and support the person—I told her about the human rights lens that we use. If it impacts the person negatively or positively, we are going to speak out, campaign, and participate in court challenges. And if you don't pay the clinicians who are going to do this sensitive work fairly, then no one is going to do it and people won't be able to find the help they need."*

*"... when we talk about MAiD, we are talking about the provision of a new and fundamental*

*human right in Canada. Medical assistance in dying is one of the most important human rights issues for personal autonomy in past 50 years."*

*"Our organization is guided by what is in the best interest of the person—the vulnerable and often frail person seeking to understand their choices in the face of intolerable and enduring suffering. In the fall of 2016, a bio-ethicist told me, when it comes to medical assistance in dy-*

*ing everyone—the person, their loved ones, and the healthcare practitioners involved—must all have a high quality experience. Without that high quality experience, clinicians may become discouraged, disillusioned and ultimately dissuaded from supporting patients who request MAiD."*

*"With the available data, assisted dying from January-June 2017 accounts for .9% of all deaths in the country. It is possible that number could grow to 1% by the end of 2017, and even higher in the coming years. But what does that really mean? In human terms—the kind we like to use at DWDC—it means thousands of people who don't have to suffer intolerably and indefinitely."*

*"And for those of you in a jurisdiction where assisted dying has not been realized, I think it might be even more helpful for you to think about this as a human right. Human rights are universal, inalienable, and indivisible. If your state, province, or country doesn't have legal or decriminalized assisted dying, it doesn't mean that the human rights doesn't exist in your jurisdiction, it just means it hasn't been realized—yet!"*

# The Ancients Had It Right!

By L. G. Lindsay

In Greek mythology, Charron rowed the dead across the river Styx to the underworld. It's different today. If we fill out correctly an Advanced Health Care Directive (AHCD), we might be ferried across the river with peace and dignity: A medical caregiver or maybe Morpheus's sister Benzodiazepine guides us to Hades. But is this really how we cross Styx today?

"We really don't have a language to talk about these issues," said speaker Ruth von Fuchs, president of Right to Die Society of Canada. Merely raising the question is deemed controversial in some circles. "Not everyone agrees upon the desirability or need for hastening death to end terminal suffering," said keynote speaker Shanaaz Gokool, CEO of Dying with Dignity Canada. Shanaaz suggested opponents of the right-to-die movement often base their objections upon the theory of atonement: To reach heavenly discharge one must first attain redemption through suffering.

Their respective, home (legal) jurisdictions influenced how speakers framed issues surrounding "hastened death." Another keynote speaker, Dr. Stephanie Green, co-founder and president of Canadian Association of Medical Assistance in Dying Assessors and Providers, spoke about legal constraints and patient vetting procedures which Canadian physicians meet before they may participate in physician-assisted dying. Several US-based speakers talked about volunteering their technical know-how to terminally ill in the 44 US states where physicians neither may write

nor administer scripts which hasten their patient's death. Canadian speaker Juergen Dankworth from Australian-based Exit International referred to a "Do it Yourself" ("DIY") model which contemplates un-

restricted adult access to voluntary euthanasia regardless of legislative permission or medical assistance.

A need for end-of-life planning was a major take-away by conference attendees. Several speakers addressed the usefulness of an AHCD, which conveys one's final wishes for end-of-life medical care. Is an AHCD binding upon the patient's personal advocate, next-of-kin, or attending physician? Ambiguous wording in an AHCD might be hard to interpret or indeed might not apply to the circumstances in which a patient finds himself at life's end; or a patient's final wishes for death with dignity conflict with the moral or religious beliefs of an attending physician or a hospital's institution-

al policies. And, regardless of personal beliefs, the attending physician might be concerned about the parlous, legal implications of hastening death even where his terminally-ill patient had insisted upon it in an AHCD.

Some speakers did not speak, however, with a single voice on end-of-life planning. One advocated using the Physician Orders for Life-Sustaining Treatment (POLST). While not legally enforceable in all US states, a POLST both informs healthcare providers with directions for a patient's end-of-life medi-



**"If we fill out  
correctly an AHCD,  
we might be  
ferried across the  
river with peace  
and dignity..."**

ANCIENTS continued on page 8



# Vermont Study Points Out Mixed Value of Information

There's an often quoted line in the movie, *Cool Hand Luke*: "What we have here is failure to communicate." The same failure frequently appears in hospitals and in end-of-life discussions with doctors and family members.

At the conference, Dr. Mara Buchbinder reported on her project, Vermont Study on Aid-in-Dying, published in the *Journal of Medical Ethics*. Focus has been on a unique feature of Vermont's Aid-in-Dying (AID) law: the patients' right to information. Is it beneficial or not to inform patients of their option? Is it mandatory for doctors to inform patients of the AID option or can conscientious objectors consider this discretionary? An associate professor and medical anthropologist, Dr. Buchbinder has discovered that, while communications

is often helpful, there are times when it might best be avoided.

"Physicians may determine it inappropriate, and potentially harmful, to inform patients that AID is a legal option if the patient's underlying medical condition will impede her ability to self-administer and/or ingest the medication... [P]hysicians should restrict disclosures about AID to patients who have already indicated willingness to receive information about their prognosis."

Such conversations can be uncomfortable for both parties. "Physicians may fear that such a disclosure will signal a loss of hope or abandonment, or result in a patient's mistrust or deeply offend patients that hold opposing views." On the other hand, it "provides an opportunity to revitalize social connections through death." ■

## Should physicians inform patients that aid-in-dying is an option?

### CONS

Signaling a loss of hope or abandonment

Damage to the patient-provider relationship

Communicating an implicit endorsement of the option

Possibility of influencing the patient's decision

### PROS

Professional responsibility to inform patients about options

Patients might not otherwise know it's an option

Patients who do know are more educated/advantaged

Waiting for patients to initiate raises justice concerns

cal care and also supplies providers with legal immunity. Another speaker, Dr. Richard Stuart, advocated on behalf of using a more nuanced template for standardizing the protection of patient's rights called Medical Orders for End-of-Life Intervention (MOELI). The MOELI consists of a three-part living will which includes a personal statement, an AHCD, and a durable power of attorney (POA). *Note: Visit the FEN website for Dr. Stuart's Six Step Living Will.*

Late onset dementia or Alzheimer's disease can bar the implementation of end-of-life planning. Even in jurisdictions which allow physician-assisted dying, doctors must affirm whether the terminally ill patient has "capacity" to understand the next steps which medical care staff shortly will take to hasten their patient's death. Some AHCDs include a so-called "Ulysses" clause by which the terminally ill advises his personal advocate and doctor to disregard oral instructions which might be uttered in extremis at life's end. In effect, a Ulysses clause says: "Honor what I asked you then, not what I might ask you now!" Ancient Greeks certainly would not have been puzzled if Odysseus had said to Charron: "Whatever I might utter today, please continue to paddle me across the river Styx. The wily Ulysses who I was then is not the confused and frail Odysseus who slumps before you now!" ■

---

## Whadda Ya Say, Doc?

*Quotes by Dr. Aroop Mangalik from the conference:*

*"A lot of doctors think that, if a patient dies, it is their fault."*

*"Care is not the same as treatment."*

*"Denial of death is worsened by false hope."*

*"Don't be intimidated by a doctor."*

## WORKSHOP PROMOTES BALANCE

*By Steve & Diane Sewell*

John Abraham has educated thousands of people, over a period of four decades, on how to prepare themselves for getting the death they want, and how to protect themselves from those who will try to preserve a life that has no quality remaining, and no real possibility of returning to a healthy state. His encyclopedic knowledge of the proper preparation of advanced directives provides a framework for planning to have the death you want, without the invasive intervention you do not want.

We all consider death in abstract terms, perhaps recalling the experiences of friends or family members who have died. It is an entirely different thing to contemplate, indeed to plot and plan our own death with the goal of dying well, with minimal pain and suffering and, moreover, with minimum interference from well-meaning family and medical professionals who wholeheartedly reject the idea that we want a peaceful end to our lives.

Whether the acknowledgement that the "balance" has shifted in ourselves or in the life of a loved one, it becomes essential to protect the dying from the social and medical establishment that, without regard for the "patient," will go to extreme measures to extend the life that really wants to end in peace and comfort. John presents the facts we all need to know in order to ensure that we properly document our end-of-life wishes in a manner that is legally binding and unambiguous.

## ***Making Advance Directives Work***

*By Lisa Salazar, R.N.*

*John Abraham's advocate training was amazing. He did a great job explaining the responsibilities of an advocate, running various scenarios with different alternatives, and discussing communication techniques. The training included video case studies that were very realistic and all for the participants to exchange thoughts and interventions. This class would benefit by reaching more advocates and by issuing certificate for the attendants. Thank you, John, for realistic training on a difficult and challenging subject. Well done!* ■



# Pope's Recommendations

By Faye Girsh

Law professor Thaddeus Pope's presence in Henderson was reassuring and helpful. At this stage in our movement it is essential to know how to proceed legally. To borrow from his web page:

"He joined Hamline University School of Law as the director of the Health Law Institute in January 2012 after serving as associate professor of law at Widener University School of Law. Pope earned a J.D. and Ph.D. in philosophy and bioethics from Georgetown.

"Professor Pope uses the law both to improve medical decision-making and to protect patient rights at the end of life. He is working: (1) to balance liberty and public health, (2) to assure adequate informed consent, and (3) to develop fair internal dispute resolution mechanisms. Specific topics include medical futility, advance directives, ethics committees, and brain death."

These are some of the issues that are most troubling when it comes to using our laws and advising people concerned with directives, particularly in the area of dementia. He writes prolifically, and addresses clinicians and those of us who work with people who are trying to figure out how to die peacefully with a minimum of red tape and knowing that their wishes will be respected.

His presentation at the conference involved developing an advance directive to permit withholding food and hydration when a person has become incompetent. The new directive from End of Life New York embodies Pope's recommendations. He pointed out that all current aid-in-dying laws require the person to be terminal and mentally competent, which rules out people

already suffering from dementia and who are not terminal within six months. He reasons that what is left for them is VSED (Voluntary Stopping Eating and Drinking) and that one can make this happen with a reliable and assertive healthcare agent expressing your wishes when competent in a valid directive.

I agree that this approach is often what's left in advanced dementia but I am not sure that this is the ultimate solution for hastening the death of an incompetent person. I worry that skilled nursing facilities may interpret their regulations to mean that food and water must be given. It can work when a person is taken out of the facility but then it could be a suspicious death. A request that spoon-feeding be stopped will have to be adjudicated to settle the issue for many nursing homes. Also, if one is not competent and being fed or medically treated against their stated wishes, it would be necessary to monitor their care 24/7. An army of people monitoring directives of incompetent people in institutions must be trained to make sure unwanted treatments are not administered. Also, even in advanced dementia, the person may enjoy food and drink and may suffer by not having these removed. One other problem is the dubious legal status of the Advance Directive. It may not be easy to enforce the wishes expressed in a document with questionable legal value. The POLST, or equivalent, might be a better place to start.

To have a lawyer of Professor Pope's stature, knowledge, and accessibility will help us solve these problems faster. And, it is always reassuring to have a Pope at our conferences. ■

*Professor Pope uses the law both to improve medical decision-making and to protect patient rights at the end of life.*

# Internet's Favorite Mortician

By Linda Banez

Caitlin Doughty contributed to Final Exit Network's conference in two parts—in a comedic routine Friday night and in a keynote talk Saturday morning—but her influence in the dying-with-dignity movement already goes beyond FEN's conference and is likely to extend long past the conference.

Friday night after dinner, her humorous (and quite frank) routine entertained as well as educated her audience. This writer didn't ask Ms. Doughty to what extent that comedy routine was staged, but as she pulled one question after another from a basket and responded unhesitatingly with a detailed, insightful answer, I wondered: Were the erudite answers spontaneous or had the questions been rehearsed earlier? From personal queries such as, "When you die, how do you want your body disposed of?" (answer: leave my body for wild animals; I've been eating them all my life) to more academic concerns, "How long is it before a dead body smells?" (answer: 72 hours), the questions were varied and their order seemed random, but there may have been some staging involved. The questions and answers were fascinating.

On Saturday morning, Ms. Doughty offered a detailed treatise on the problems she had faced as she introduced her progressive perspective on death and the dying procedure to a society entrenched in death phobia. In her presentation, she included copies of on-line communications that she had exchanged with opponents. In some cases, the e-mails revealed how skewed our present system is. The adamant insistence that a proper burial can only take place when the corpse is interred in a satin-lined, carved, mahogany coffin takes on a new slant when it's revealed that the argument is offered by an elected official who happens to own a large casket company.

The dying-with-dignity movement in the United States is about thirty-five years old and was begun by brave, forward-thinking, compassionate people who were not much older than Ms. Doughty is now. She exemplifies a new generation in the movement—a movement that is expanding in ways unimagined before internet technology and before the current subtle shifts seen recently in common conceptions about death. Her contribution to this movement will extend, this veteran (of only some thirteen years) predicts, in ways far beyond Final Exit Network's conference. ■



*Saturday Keynote Speaker Caitlin Doughty: Her latest book "From Here to Eternity" reveals long-held beliefs about death and dying around the world.*





# Shelly's Tragic Demise

By Barry Sinrod

*After his wife's decline and death, Barry Sinrod wrote a warning for others. When Barry was unable to attend the conference, his story was read by Mike Morse. Here is a condensed version.*

**T**he ability to end your life as you wish is limited, and our personal right to determine the time, manner, and mode of passing is not ours to decide. Therefore, I have dedicated the rest of my life to helping those desiring the right-to-die on their terms to be able to do so.

Following three years of incorrect diagnoses, my wife Shelly was found to have Parkinson's disease. In speaking about the future, she repeatedly made me promise that I would not let her suffer. She neither wanted to wind up in a nursing home, staring at a wall, or living trapped in a world of fear and loneliness. I gave her my solemn word that I would never let that happen. Further, I told her if it was me, I would want the same.

She was my other half, she completed me and was my best friend. I intended to keep the promises we made. As time went by, she slipped further away mentally and physically. She reminded me time and again to not let her suffer and be in a world where she knew no one and again, I promised her without a moment of hesitation to follow that promise.

Sadly, I will forever live with the knowledge that I couldn't keep the promise I made to her. This is something that will haunt me forever.

She eventually needed medication. Within a month she fainted in a restaurant and, while it lasted less than a minute,

**"I told her it was  
time to stop  
playing and we  
could spend our  
time together.  
She agreed."**

**SHELLY** continued on page 15

# Take Charge of Your Critical Healthcare

*By Richard B. Stuart, DSW, ABP*

Lloyd was suffering from intractable pain associated with metastatic cancer in his bones. His advance directive stated “no heroic measures” but did not stipulate which measures he considered heroic. His POLST form (Physician Orders for Life-Sustaining Treatment) stipulated no breathing machine or antibiotics, but because it did not mention artificial feeding, a PEG (percutaneous endoscopic gastrostomy) tube was placed in his stomach. His arms were restrained to prevent him from removing the irritating feeding tube.

Sally, 82, decided long ago that she wanted comfort-care-only if she had a terminal illness. Now living with dementia, she is deemed to lack the capacity to request the treatment she wants. As a result, she has been on life support for months and could linger in that state for many more months or years.

Sam was in his late 80s with a good quality of life. Because of his advanced age, he stipulated DNR (do not resuscitate) on his POLST. One day, while he was hospitalized for a necessary procedure, he lost consciousness due to an adverse reaction a new drug he had begun taking. The hospital in which he was treated had a firm policy that patients’ POLST requests must be respected. Since he had a DNR, he was offered only comfort care and died soon thereafter.

With better planning and better documents in place, these people could have had a much better chance to avoid these unwanted situations.

Everyone 18 and older can benefit from creating a comprehensive, specific living will. One way to do that is to use the website [www.6stepslivingwill.org](http://www.6stepslivingwill.org) to download a free three-part living will. A Personal Statement articulates your values and the sources of mean-

ing in your life, and the way these frame the kind of end-of-life care you would like to receive. An Advance Directive summarizes your values and states your preferences regarding resuscitation, the common components of life-sustaining interventions (defibrillation, intubation, hydration and nutrition by inserted tube, dialysis, and pacemaker), and several other essential decisions. The Durable Power of Attorney for Health Care guides the selection of a healthcare surrogate and suggests ways to verify that this person understands your wishes and has the ability to present them when you can’t speak for yourself. While on the site, you can also complete Step 5, a two-page summary of who you are, your current illnesses, and the medications you are currently taking. It is useful to keep a continuously updated copy of this form with you to show to the multiple providers you are likely to see if you are gravely ill. Your surrogate can also show it to first-responders if an aid-call is requested. If Lloyd and Sally had completed advance directives, they might have been spared the burden of unwanted treatment.

The next useful action is to ask your provider to initiate a MOELI (Medical Orders for End-of-Life Intervention, rhymes with Holy) to replace the more commonly used POLST. These documents both offer a way to have your end-of-life treatment requests entered into your medical record, but the MOELI offers valuable options not included in the POLST.

The MOELI allows non-terminally ill people 80 or older to stipulate their end-of-life care wishes while they still have the capacity to do so; the POLST does not. Having a MOELI might have spared Sally from having to undergo treatment she fervently hoped to avoid. Another major difference between the documents is that POLST

**TAKE CHARGE** *continued on page 15*



# Coercion Can Come From Opposing Directions

By Lowrey Brown

**D**r. Stefanie Green's name may be familiar in this crowd as an outspoken provider of medical assistance in dying (MAiD) in Canada. In her presentation, she described the requirements of Canada's law and how she evaluates a patient's eligibility. Her evaluation includes ensuring that the patient is competent to make the choice and that the choice is, indeed, the patient's, unencumbered by undue influence from another. She spends considerable time with each patient and will also speak with family members or friends, but, she explained, once she is convinced the decision to seek MAiD comes from the patient, then "the rest doesn't matter" (the rest of the opinions, not the rest of the requirements).

Another speaker, Maia Calloway, had worked in film production until progressive multiple sclerosis took its toll. Calloway is faced with a future of increasing physical and mental limitation, and decreasing autonomy and ability to engage in ways that are meaningful to her. Her family is strongly religious and opposes her wish to die before her quality of life sinks to a level that is unacceptable to her. Without her family's knowledge, Calloway got to Switzerland early, fearing being unable to make the trip when her physical ability declined further. She was able to travel some and take advantage of her time there, but was haunted by her family's condemnation. She decided to come back, at least in part, to see if she could bridge some of the distance between her family and herself.

**"Individuals should not be coerced into ending their lives before they wish, and individuals should not be coerced into enduring more suffering than they wish."**

I was struck by the contrast between Dr. Green's focus on her patients' choices, regardless of the opinions of family and loved ones, and Calloway's description of feeling forced underground, carrying the burden of family disapproval, and returning to see if she could smooth those connections. As a result, she finds herself looking at a steadily-closing physical window of opportunity to get back to Switzerland, should she wish to pursue that option, or any self-deliverance option here in the US.

Opponents of death with dignity often cite, as a reason physician-assisted death should be prohibited, the possibility of vulnerable individuals being coerced into choosing to end their lives. Certainly, the concern is valid, even if the proposed solution of blanket-prohibition is not (if the possibility of abuse were a valid reason for prohibition, all of society's institutions would be prohibited). Calloway's situation is a reminder that coercion can come from any direction. Individuals should not be coerced into ending their lives before they wish, and individuals should not be coerced into enduring more suffering than they wish. Unfortunately, while Dr. Green can screen for patients who have been bullied into requesting MAiD, she cannot protect against the coercion that keeps a patient from seeking medical assistance in the first place. The more difficult society makes it for individuals to choose self-deliverance, inside or outside of the medical system, the easier it is for those who oppose that choice to impose their values upon those around them, and this coercion is often overlooked. ■

# Good Endings Book Club



## Dealing with Doctors, Denial, and Death by Aroop Mangalik, M.D.

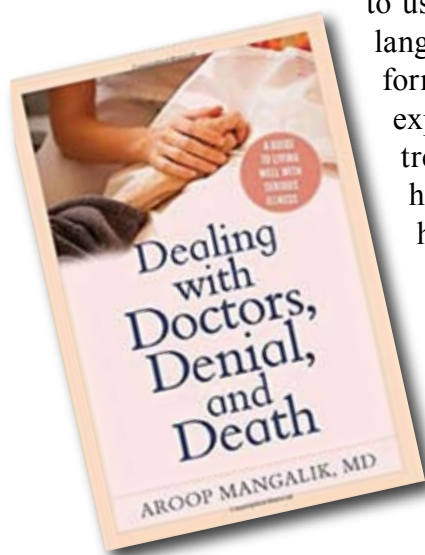
Reviewed by Huck DeVenzio

Hearing Dr. Mangalik's perceptive observations at the conference (see Whadda Ya Say, Doc? on page 8), I figured that his book was probably worth reading. I was right.

This text is aimed at the general public, but would seem to make beneficial reading for medical professionals. The author covers denial of death and the difficulty for some people to deliver and accept bad news. He points out the value of hope and optimism, but says, "False hope does not help anyone." He believes religion can bring comfort, but shouldn't lead to distress. He distinguishes between care and treatment, and criticizes over-treatment. He urges doctors

to use simple, non-technical language in presenting information on a disease, its expected course, available treatments, and the likelihood that a treatment will help and for how long. He advises doctors to treat the patient, not the ailment. He warns families that the desire to do everything possible can cause more harm than benefit.

The book does an excellent job of identifying problems and explaining how they have devel-



## Presidential Views

FEN president Janis Landis offered two observations:

*"In the late Sixties, people moved to Canada to save their lives. Now they go to end them."*

*"People tend not to pay attention until we express an interest in dying. If you're in an institution having trouble getting medical attention, just say, 'I want to die.'"*

oped. If it has a shortcoming, it is in recommending solutions. Mangalik admits, "As of now, the best that you as a patient can do is to ask questions and be sure that you are not subjected to unnecessary treatments or tests." It is difficult for anyone lacking a medical degree to recognize futile treatments, but awareness of their existence and of the tendency for doctors and institutions to do more rather than less could reduce the likelihood of procedures, medicines, and political decisions that encourage over-treating.

## Extreme Measures

by Jessica Nutik Zitter, M.D.

Reviewed by Jerry Metz, M.D.

*A past newsletter included a rather negative review of this book. The present reviewer had a different opinion.*

Our "Dying in the Americas Conference" in March had as its objective "Reframing the conversation and reality of death and dying..." I recommend a recent book by an articulate and highly qualified conversationalist on this subject, Jessica Nutik Zitter, M.D. Her "Extreme Measures—Finding a Better Path to the End of Life" paints a panorama that can make the Conference experience more informative to minds already properly primed. Her solid stance, one foot board-certified in palliative care and the other certified in pulmonary/critical care, provides her a unique perspective. Her blunt honesty includes unusual willingness to be self-critical: "I came to see that in our zeal to save life, we often worsened death."

*This book is a treasure!* ■



one week later it happened again. She was hospitalized to determine the cause.

The next morning in the hospital, a young girl entered the room to say Shelly was being scheduled for a pacemaker. I thought she was in the wrong room, but the doctor told me it had to be done.

By 2010, we saw major changes in Shelly's condition. She was slower and her cognitive ability was slipping. We revisited our attorney to ensure that our Advance Directives were the latest and best.

I knew we were in trouble when my wife, who had been playing cards and mah-jongg five days a week for 20+ years, suddenly started making mistakes. The women, who had been her friends for all these years, were brutal to her and repeatedly chastised her for her mistakes. She often came home crying at the way she was treated.

I told her it was time to stop playing and we could spend our time together. She agreed. But, as soon as that happened, virtually every friend of ours disappeared from our lives. We were isolated; no friends, no social life. Our best friends, with whom we often traveled and were with seven days a week, backed away from us. The wife of this couple, who was my wife's very best friend, could not bear to lose her place in mah-jongg and deserted us.

It was a very sad time.

Cognitive tests showed she was quickly drifting into dementia. It was clear that she was failing badly. I was falling apart as my wife had to be moved out of our bedroom into the guest room. My wife of 50 years was essentially gone from my life. She was breathing, but no longer knew who I was and no longer recognized our children.

It was at this time I presented our homecare Hospice unit with the Advance Directive and said, "Let her go!" That was her written wish and strong desire. In my mind, she was now "gone" except for breathing.

They refused, saying from their medical perspective, she was not at the end. I was nearly insane with grief and total despair.

Believe it or not, several doctors told me, if I wanted a quick demise, to place her in a specific dementia facility because, "This facility will kill her within days as it is ridden with contagious and fatal diseases!" I put her in there.

It was a disgusting place. Fifty patients were in chairs in front of a TV and not one sound was heard.

All were "dead" except for breathing. Several were on the floor. I watched in horror as not one nurse moved to put patients back in their chairs. I screamed at them, but no one answered.

By now she was "frozen" in one position; eyes open but without a gaze. In the last month, they brought a spoon to her mouth three times a day. "Why?" I asked. "It was the law," they said.

Shelly finally passed on June 6, 2014. They had tortured her for nearly four years. I have realized that I—we—must work every single day to get the U.S. to change its rules and allow people the right-to-die without any further explanation required beyond their specific instruction in their Advance Directives and Living Will. ■

## TAKE CHARGE *continued from page 12*

limits your choices to CPR (cardiopulmonary resuscitation) or DNR (do not resuscitate). In contrast, the MOELI offers a crucial third option (*DO resuscitate only if my heart stopped due to a temporary reversible event, e.g. anaphylactic shock*). Having this option could have increased the likelihood that Sam would be resuscitated when he still had an acceptable quality of life. Finally, while most POLSTs arbitrarily stipulate only two common life-sustaining treatments, the MOELI provides an opportunity to stipulate whether, and if so how, they would like to undergo each of the six common procedures. This eliminates some of guesswork in managing terminal illnesses. It could have bolstered Lloyd's chance of receiving the care he wanted and avoiding procedures he did not want.

You can learn more about the MOELI on the 6-Steps website. You will find an overview of how to use it by scrolling down the "Guide" tab. There's a reproducible copy of the form at the "Entering your preferences in your medical record" under "More Information" tab.

Good healthcare is increasingly dependent upon an active collaboration between patients and providers. Creating a solid living will and using it as the foundation for a MOELI are effective ways to make your preferences known. Doing so can greatly increase the likelihood that the care you receive is the care you want.

*Richard Stuart introduced the merits of the MOELI at the Nevada conference.* ■

## New Suit Filed for Free Speech

Final Exit Network has brought a civil rights lawsuit in federal court to overturn Minnesota's law against assisting in a suicide, saying Minnesota's law violates the First Amendment-protected right to freedom of speech.

The Network's lawsuit was filed on April 16, 2018 in the Minneapolis office of the United States District Court for Minnesota. U.S. District Judge Joan N. Ericksen was randomly assigned to preside. A former associate justice of the Minnesota Supreme Court from 1998 to 2002, Judge Ericksen is now being urged to overrule that same court.

Unique in the country, the Minnesota statute—as effectively rewritten by the Minnesota Supreme Court—makes it a crime to give information about how to induce one's own death to anyone who is contemplating self-deliverance. Under the Minnesota Supreme Court's interpretation, it is not a crime to hand out copies of Final Exit to strangers on the street, but it is a crime to hand a copy of the New York Times bestseller to someone who is thinking of using the information in the book to terminate irremediable suffering.

It would even be a crime for a librarian to show such a person where to find the book on the library's shelves.

"This absurd interpretation of the law must not be allowed to stand," said FEN's president, Janis Landis.

In 2015, after three years of convoluted and confusing pretrial proceedings, Final Exit Network, Inc.—only the corporation, none of its courageous volunteers—was convicted of a felony, "assisting in a suicide," in Hastings, Minnesota. It was the first time the organization had ever been convicted of any type of crime.

Sentenced to pay a fine of \$30,000, plus "restitution" of \$3,000, Final Exit Network paid the penalty and appealed. The Court of Appeals of Minnesota affirmed the conviction and the Supreme Court of Minnesota and the Supreme Court of the United States both refused to consider the case. The U.S. District Court lawsuit starts a new legal process by seeking a judgment that the Minnesota law is unconstitutional and a permanent injunction that Minnesota discontinue applying its law in a manner that infringes on the First Amendment-protected rights of Minnesota citizens.

The federal civil lawsuit will probably take six months to a year to be completed. If the federal court denies relief to FEN, FEN will be entitled to appeal to the Eighth U.S. Circuit Court of Appeals. If FEN is not successful there, FEN will have another opportunity to file a petition seeking review in the Supreme Court of the United States. ■

### BOARD OF DIRECTORS

Janis Landis, MA, President  
Kevin Bradley, MDiv.  
Ronald Liesemer, Ph.D.  
Cameron Linen, MTS, MS  
Brian Ruder  
Judy Snyderman, MBA, Treasurer  
Martin Seidenfeld, PhD  
Tom Tuxill, MD  
Gary Wederspahn, MA

### ADVISORY BOARD MEMBERS

Linda J. Banez  
Schera Chadwick, MA  
Ila DeLuca  
Huck DeVenzio  
Ruth von Fuchs, MA  
Faye Girsh, EdD  
Derek Humphry, Chair  
Richard MacDonald, MD  
Wendell Stephenson, PhD, President Emeritus  
Lee Vizer, MA

### NEWSLETTER STAFF

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

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

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



YES! *I want to support this important work.*JOIN/  
DONATE  
NOW**EASY CONTRIBUTION METHOD**

1. Mark your check as a membership and/or donation - SAVE your receipt at the bottom of this page.
2. Place your check in the supplied envelope, affix your address label, stamp, and drop in the mail!

**1 FOR NEW MEMBERS, INFORMATION CHANGE, GIFT, OR CREDIT CARD PAYMENTS:**

Affix a label, or if your name is on the label on the reverse side of this page, skip to step 2.

NAME \_\_\_\_\_ SPOUSE/PARTNER \_\_\_\_\_

ADDRESS \_\_\_\_\_ CITY/STATE/ZIP \_\_\_\_\_

PHONE \_\_\_\_\_ E-MAIL \_\_\_\_\_

How did you learn about us? \_\_\_\_\_

Do you prefer to receive the newsletter by email? Yes \_\_\_\_ No \_\_\_\_

**2 MEMBERSHIP: CIRCLE ONE****NEW:** INDIVIDUAL \$50 COUPLE \$75 **LIFE:** INDIVIDUAL \$500 COUPLE \$750**RENEWAL:** INDIVIDUAL \$50 COUPLE \$75 **CONVERT TO LIFE:** INDIVIDUAL \$500 COUPLE \$750**3 DONATIONS:**

Grassroots: \$20 \$50 \$75 \$100 \$200 \$500 Other \_\_\_\_\_

Major sponsor: \$1,000. \$2,000. \$5,000. \$10,000.

☐ YES, please list me as  
a sponsor in program  
materials**4 PAYMENT:**

DONATION \$ \_\_\_\_\_

LEGAL DEFENSE \$ \_\_\_\_\_


MEMBERSHIP \$ \_\_\_\_\_

TOTAL \$ \_\_\_\_\_

☐ CHECK ☐ CREDIT CARD☐ MasterCard ☐ Visa ☐ AmEx ☐ Discover

Credit Card # \_\_\_\_\_

Exp. Date \_\_\_\_\_ CSV \_\_\_\_\_

☐ I am interested in providing an estate  
gift to support this worthy cause.PLEASE HAVE A NETWORK  
REPRESENTATIVE CALL MESignature \_\_\_\_\_ 

SEND THE PORTION ABOVE THIS LINE WITH YOUR PAYMENT IN THE ENCLOSED ENVELOPE; SAVE PORTION BELOW

RECEIPT FROM: FINAL EXIT NETWORK, P. O. Box 10071, Tallahassee, Florida 32302

RECEIVED FROM: \_\_\_\_\_

DATE: \_\_\_\_\_ DATE TO RENEW NEXT YEAR \_\_\_\_\_

PAID BY: \_\_\_\_\_ CREDIT CARD \_\_\_\_\_ CHECK: # \_\_\_\_\_

PAYMENT FOR: MEMBERSHIP (AMOUNT \$ \_\_\_\_\_)

DONATION (AMOUNT \$ \_\_\_\_\_)

**SAVE THIS  
RECEIPT  
FOR YOUR  
RECORDS**

FINAL EXIT NETWORK is a nonprofit 501(c)(3) corporation dedicated to ensuring death with dignity. Membership and donation processing takes 3-4 weeks. Donations and membership dues are tax-deductible to the full extent allowed by law. QUESTIONS? 1-866-654-9156