FINAL EXIT NETWORK
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FEN

THE GOOD DEATH SOCIETY

You Can Help!

CONTENTS

WANTED
Volunteer Help

The outreach program is seeking volunteers to fill the following positions:

Head of media relations
Head of press relations
Writers
Speakers
Affiliate leaders

For more details, contact
Gary Wederspahn
gary@intercultural-help.com.

Volunteer Positions at FEN

Many of the articles in this issue focus on volunteerism at Final Exit Network—the positions filled by volunteers and the volunteers who fill them.

It takes a wide range of capable and engaged members to operate a successful, mostly volunteer organization. FEN is no exception. By discussing the positions, it is hoped that we identify the jobs available to volunteers and also recognize some of those who give their time and energy to relieving the suffering of others. Not only is the organization strengthened and available funds extended, but the volunteers accrue personal benefits as well.

FEN vice president Brian Ruder, himself a volunteer, says "FEN would not exist without our volunteers, who are dedicated to furthering end-of-life choices. We have only one full-time and two part-time consultant 'staff.' We have enough volunteers to handle our current volume of exits, but we could always use people with the ability or resources to attract new members or gain greater awareness for FEN."

Renew your membership online:
www.finalexitnetwork.org

"You make a living by what you get. You make a life by what you give."
~Winston Churchill

"Volunteers do not necessarily have the time; they just have the heart."
~Elizabeth Andrew

"The meaning of life is to find your gift. The purpose of life is to give it away."
~William Shakespeare

Depending on Volunteers

Administration

FEN is overseen by volunteers serving in three primary roles.

- Officers
- Executive Board
- Advisory Board

We have a president (Janis Landis), vice president and expected next president (Brian Ruder), and treasurer (Judy Snyderman). They are guided by an Executive Board which convenes monthly on a conference call. They vote on issues of importance. At the time of this writing, the Board has nine members, each of whom is responsible for a portfolio function, such as policy, outreach, and finances.

Also, subject to Board approval, is an Advisory Board consisting of ten members chosen because their experience or insights could be valuable to the Network. They, too, participate in the monthly Board meeting but they do not get a vote.

Committees

Two committees serve essential functions:

- Oversight Committee
- Medical Evaluation Committee (MEC)

The MEC currently comprises six members who are all doctors, although being a physician is not mandatory. From every candidate applying for exit services, a personal statement, medical record, and interview commentary is sent to three appropriate members for confirmation that the person qualifies for our services. They may accept or reject the candidate, or they may require more documentation.

When non-routine situations arise, the three-person Oversight Committee resolves questions.

Exit Services

The heart of FEN's work revolves around the exit volunteers. That's where the pedal hits the metal, where the chip reaches the guacamole. There are three types of these volunteers:

- Senior Exit Guides (8)
- Associate Exit Guides (15)
- Exit Coordinators (7)

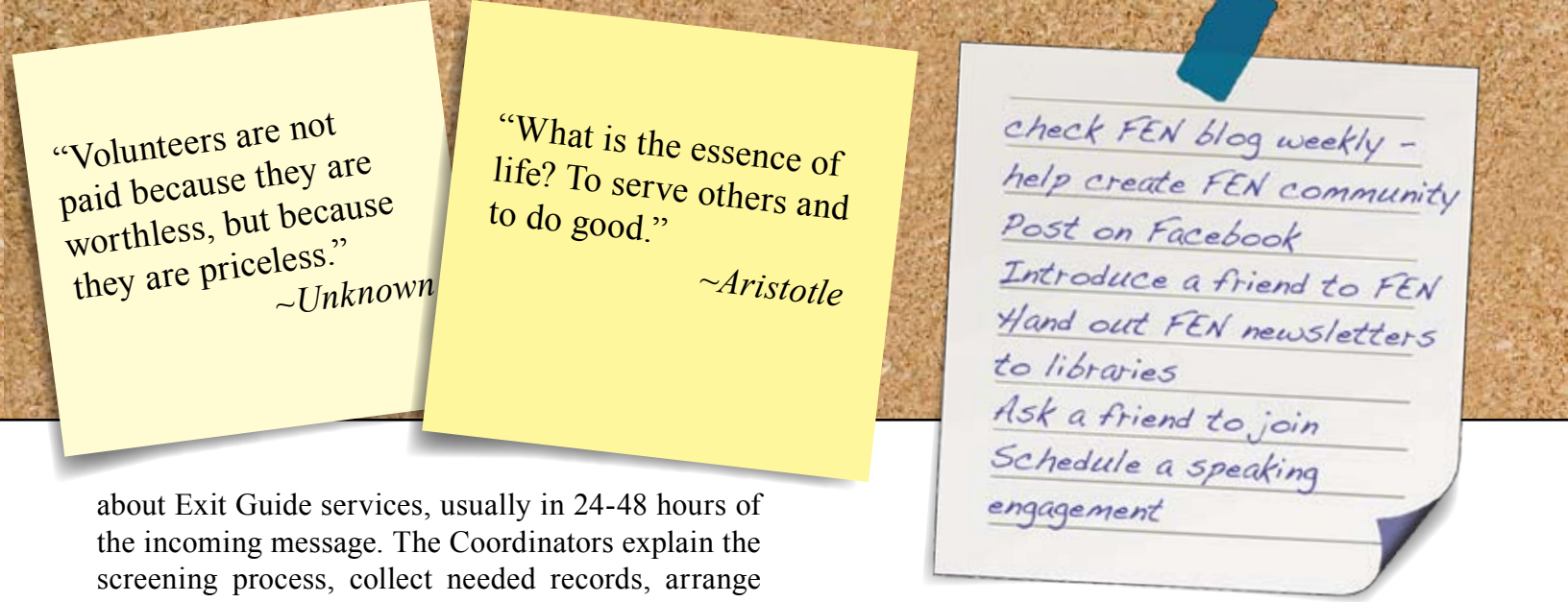
All three undergo extensive training before taking an assignment.

Coordinators are usually the first contact with those seeking Exit Guide services. They return calls placed and e-mails sent to FEN asking for information

Board Member Portfolios

In addition to their voting and decision-making duties, board members each have a portfolio of individual responsibilities which include oversight, guidance, and support for key FEN functions:

- Janis Landis, President: Executive Committee
- Brian Ruder, V P and President-elect: Operations
- Judy Snyderman, Treasurer: Financial Management
- Tom Tuxill, MD: Policy Committee
- Marty Siedenfeld: Development
- Gary Wederspahn: Outreach
- Kevin Bradley: Online Course Development, Counseling
- Cameron Linen: Executive Committee
- Ron Liesemer: Research



about Exit Guide services, usually in 24-48 hours of the incoming message. The Coordinators explain the screening process, collect needed records, arrange for a detailed interview, get a feel for the inquirer's needs, often can determine if the inquiry is likely to be accepted, send an application packet of material to the MEC, and provide needed information to a Senior Guide if the applicant is approved for Exit Guide services by the MEC.

The Senior Guide conducts another interview, designates an Associate Guide, and heads the exit team. If at any point the Senior Guide doubts the appropriateness of an exit, the process is halted. If not, the Senior Guide visits at least once to demonstrate proper use of the recommended method. Through all phases he or she asks if the candidate is certain of their intentions and realizes the finality of this decision. The Senior Guide is usually present at the exit unless the candidate prefers otherwise.

Associate Exit Guides may be gaining experience to be a Senior Guide, or they may prefer the responsibilities of an Associate. Frequently they attend exits; nearly all Associates conduct interviews with candidates.

Although being an exit guide appears to be a somber duty, most of them say the gratitude of the candidate and family is uplifting and inspirational. The beauty of a peaceful exit is unforgettable.

The Speakers Bureau

The Speaker's Bureau is part of FEN's outreach effort, aimed at both attracting new members and promoting end-of-life options.

It consists of about 18 volunteers, including Bill Schoolman. As a member of the Bureau, he conducts presentations for groups requesting them in his area of South Florida, and he tries to interest groups in learning about FEN. "It's not easy setting up speeches," says Bill, "because, although it's as much a part of life as is birth, people don't like to discuss death."

Bill was active as a speaker and a Florida state officer for the ACLU for 10 years before volunteering for FEN about 1-1/2 years ago. "I have long believed in civil rights, and there may not be a greater right than managing how you die." He also had a personal tragedy when his partner died following an attempted kidney transplant and the hospital ignored a legally proper DNR order.

He's hopeful for the future of death with dignity, but sees it requiring a lot more speeches.

Bill Says…

"Thirty years ago, about 70% of people died at home, surrounded by loved ones. Today, about 70% die in hospitals, surrounded by strangers and machines, even though most people, including most doctors, say they want to spend their last days at home. We should show at least as much compassion to our family members as we do to our pets."

- Bill Schoolman

The Specialists

These individuals do not fit well in other categories. The volunteers, however, all have some special talent that suits their function, whether that's a technological bent that keeps FEN abreast of the latest developments in self-deliverance, expertise in legal matters, the ability to oversee our newest venture in social media, or editing this newsletter.

- Liaison with NuTech
- Attorney
- Blogmeister
- Newsletter Editor

VOLUNTEERS *continued on page 4*

"Volunteers will get you through times of no money better than money will get you through times of no volunteers."
~ *Ken Wyman*

"So, for the next three months while your brain is healing, one of our neurology volunteers, Karl, will be helping you think."

VOLUNTEERS *continued from page 3*

Affiliate Leader

In a few spots, there are active local chapters that conduct a variety of instructional and social activities. This occurs where there is a concentration of FEN members and at least one ambitious leader. A standout example is the affiliate in Arizona, but other areas also conduct programs. See "What is the Role of FEN Affiliates and Affiliate Leaders?" on page 5.

Note: The numbers of volunteers will vary depending on need and availability of suitable people. Also, some people may assume multiple tasks. (They're the overachievers.)

Advice for Volunteers

Julia Hanway has worked with FEN volunteers on programs, speaker presentations, website, and newsletter design, among other projects. This has given her a wealth of practical experience on volunteering.

"We have several jobs for people who want to volunteer," says Julia. "Most people want to be guides, but there are other opportunities that are important to the organization. For example, we could benefit from people who:

1) contribute and respond to our weekly blog and facebook page
2) respond to editorials in newspapers and magazines
3) write an article for a local publication or online group
4) find speaker opportunities for us to contact
5) drop off newsletters (available by request) at their medical offices, libraries, or retirement residences
6) hand out a newsletter or brochure to a friend who might be interested in FEN
7) invite a friend to join."

These tasks are as important as our other duties because they can build our numbers and attract more people to the death-with-dignity movement, which is a vital need to our success.

"But most members looking for volunteer work," Julia adds, "want to be exit guides. This is the heart of our activity, although opportunities for guides are rather limited. We have training for new guides only about once a year, if that often. If interested, first visit our website and become familiar with who we are. Guides must be members in good standing, and able to communicate via e-mail. You will be contacted prior to the next training session.

"Whether you serve as a guide, a speaker, or a recruiter, become comfortable in explaining FEN's mission. We do not assist in dying or help with suicides. That would be illegal except in the still small number of jurisdictions that permit physician aid in dying. However, we educate clients and support those who have been accepted in the guide services program, and we provide a compassionate presence to those with untreatable suffering or illness." ■

"Service to others is the rent you pay for your room here on Earth."
~*Muhammad Ali*

The Role of FEN Affiliates and Affiliate Leaders

By Eleanor Aronstein

In some areas, dictated largely by the fervor of the members and the willingness of a capable leader, active local chapters (affiliates) conduct programs and periodic meetings. Our membership is not concentrated in many locales, however, and organizing affiliates has proven difficult.

Five years ago, when I started the Upstate NY Final Exit Affiliate, I envisioned its role as both educational and supportive: to bring programs about FEN to the general public and to provide an opportunity for FEN members in the area to get together to share concerns and socialize once or twice a year. We have largely adhered to this vision. Over the past five years, our FEN Affiliate has presented programs at area Unitarian Universalist Churches in the upstate region as well as at various senior centers.

In addition, Aging in Place has asked for a program for their membership. All these programs have been open to the public, too. Since many people who have an interest in the topic have never heard of Final Exit Network, I look for ways to bring information to the general public, so that we may increase the potential base of members and continue to grow.

Our presentations offer attendees information on all the organizations that work in the Death with Dignity movement: Compassion & Choices, Death with Dignity New York, Death with Dignity Albany. In addition, I always have handouts, which include Living Will and Health Care Proxy forms. In NY, the Attorney General's office supplies (free) a wonderful booklet with forms and information. I use these.

During our last Affiliate Conference Call, someone suggested leaving FEN newsletters at local libraries! That is a great idea and I immediately requested a supply. When I brought them to the librarian at our Main Branch, she immediately offered to disseminate copies to the seven branches in this area. Each library has an area where local organizations leave materials for library users. Now FEN has its newsletters in those areas, too. In addition, Letters to the Editor of local papers provides another way of bringing Final Exit to the public's attention.

Finally, while I had hoped that our Affiliate would have a more active membership than it does, it appears that there is a small core of the membership which really wants us to continue, and which gets significant satisfaction from coming together as a small group and sharing, and which is totally devoted to the cause. These are sufficient reasons to continue as an Affiliate in this region.

And I must always include the women who educated me and helped me form this affiliate: Hedi McKinley. Nicole Sharpe, and Martha Schroder. They were not only my mentors, they have become my friends. How wonderful is that!

Vision & Mission

Slightly updated from previous versions

An ad hoc committee of FEN leaders felt it was time to consolidate and refine the statements that guide our actions. Here is the result of their collaboration with numerous FEN members.

Vision

That any competent person unbearably suffering an intractable medical condition has the option to die legally and peacefully.

Mission

To educate qualified individuals in practical, peaceful ways to end their lives, offer a compassionate bedside presence and defend their right to choose.

A guide and a friend react to an exit.

Sharing a Final Exit Experience

By Brian Ruder

As Final Exit Network guides, we have many very poignant experiences while being with people as they are preparing to die. Each experience is unique and makes us feel fortunate to be able to support people who have been enduring suffering and pain and want to manage their last days. We want to share one recent experience.

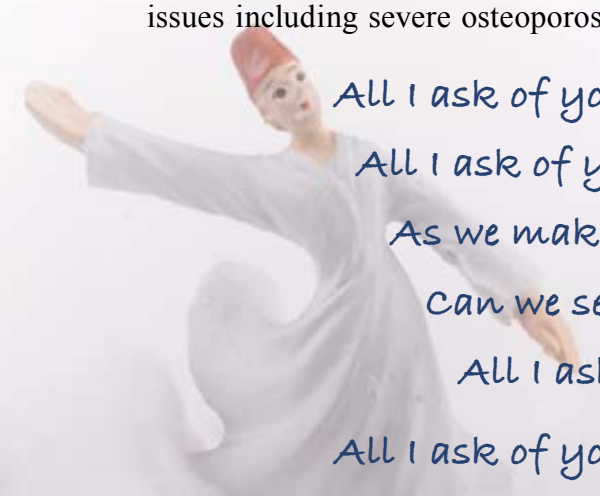
When we start our journey, we have some medical records and a letter of intent that support the reason for our visit. We have an address and a number of phone conversations as our connection. But once we arrive, we step into a uniquely personal and intimate universe created over a lifetime. Nothing can really be determined before we cross that threshold.

When we arrived we noticed the house was filled with objects both sacred and mundane. Grace sat in her big chair, now her only place, and without any trepidation reported that "today is the day and I want to go home."

Grace had lived the last 5-10 years of her life in excruciating pain from a number of medical issues including severe osteoporosis that had resulted in a few of her vertebrae cracking while walking. Each day was a difficult struggle. Fortunately, she had two friends who provided moral and physical support through her trials and who were present at the exit. Mary was a friend from the Native American community who Grace introduced to her local Sufi group. They shared many Native American rituals and a very deep friendship formed out of love and kindness. The other friend, Ann, was a nurse who had provided physical support, but had also become a very deep personal friend, because that is how one related to Grace.

After we completed our formalities, Grace said she wanted to do a little drumming and chanting. Her room had a number of instruments, which she began to play, beginning by breathing into them with the sound of a soft breeze through an open window. She also sang with an unwavering voice that was pure as crystal, a stark contrast to her failing body that could barely hold its own weight It was beautiful and allowed us all to feel the energy build in the room.

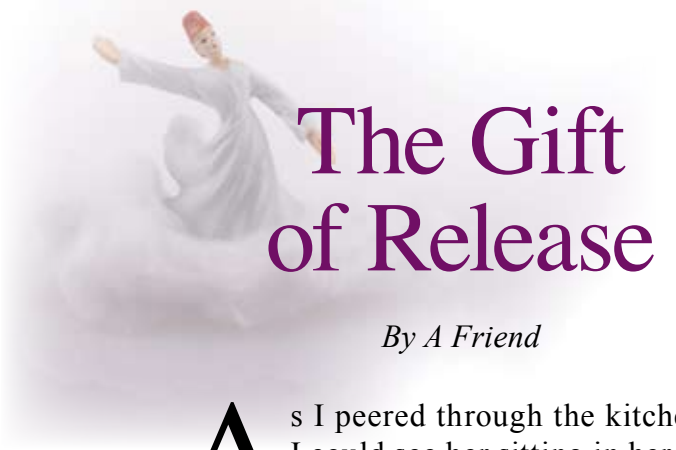
After the drumming, Grace seated herself in



All I ask of you is forever to remember me as loving you.
All I ask of you is forever to remember me as loving you.
As we make our way through all the joys and pain,
Can we sense our younger, truer selves?
All I ask of you is forever to remember me as loving you.
All I ask of you is forever to remember me as loving you.

her favorite chair with all of us sitting closely by. She then said the last thing she wanted to do was sing a song, which started out, "All I ask of you is to remember me as loving you." She sang the entire song with a smile on her face so that we could all share her love and know she was prepared to die. She died peacefully in the next 15 minutes.

What a gift to be witness to such peace and equanimity that was rooted in a greater sense of community and spirit, with the dignity and courage to approach death with ceremony and confidence, heartfelt, natural, and relaxed. It made us realize how important what we do is and how fortunate we are to be able to do it.



The Gift of Release

By A Friend

As I peered through the kitchen door, I could see her sitting in her favorite chair in the family room. As I entered, gradually she attempted to stand. I told her to sit still; I would come to her.

"No, I want to get a real hug from you."

This should have been telling. And if not, then the length and completeness of the hug should have alerted me to a change in today's schedule. I had thought that I was coming for a demonstration. It was just two days ago that she let me know that a friend of mine was also going to be there. I had encouraged her to meet with my Ayer Vedic practitioner and Sun-Moon Dancer for advice with nutritional supports and potential pain reduction plan. When they met, it seemed that they had been connected in some other time. They continued to see each other, more socially than professionally, over the past year.

She moved out of the hug and said, "I don't think this is going to be a demonstration. I woke up this morning, in extreme pain and feeling miserable. I'm done. I'm ready. You don't have to stay if you are uncomfortable."

I was the one who had found the organization [FEN], when my friend seemed so close to crossing over 16 months prior. She was in so much pain and even the simplest self-care seemed beyond her. This had been such a difficult time for someone who had always been active and involved in life. She was too ill to attend meetings, so I went to collect information, gather materials, and explain life-completion elements. I feared that she would lose so much of her abilities that she would be beyond the point of helping herself.

She had had some reprieve in function and mobility, yet the chronic pain from five, to seven, to nine vertebrae continued to fracture and collapse. Her greatest fear was becoming totally incapacitated and at the mercy of others.

I, like many of her friends, was grateful for the functional changes we observed. She and I talked about the confusion she was feeling with improved mobility, despite no significant change in her quality of life or her pain level. She spoke to me about feeling her connection with Spirit slipping away, so while I visited, we did more ceremony, drumming, and chanting. This would be uplifting at the moment, but as with many individuals with neurophysiological issues, it would wear her out for a number of days, and with fatigue and lack of distraction, the pain was most often unbearable.

So here we were and the time had come for her leaving. The final dance began, as the two of us helped her into her living room, which had become her ceremony room in the last few months. The Senior Guide and his assistant arrived, were greeted, and ushered into the space. Introductions and some initial instructions were exchanged. These two individuals readily became part of our ceremonial circle, joining ours in this most auspicious occasion. My friend spoke of memories and elements completed. She played her drum and chanted the Sound Beings into this sacred space. Then she sang a Sufi song, asking us to remember her as loving us. Tears flowed as judgment was released and all that remained was Love. It all seemed so easy, so gentle, and so final. She was at last at peace.

We were very grateful for the work and wisdom of Final Exit Network. ■

. . . remember me as loving you.

Three Difficulties with Physician Aid in Dying

By John Abraham

1. One must be "terminally ill" (doctors must pronounce six months or less to live).

And the term "terminal" is not always justly applied. I have a friend whose mother in a nursing home experienced enormous suffering and withered away to only fifty-eight pounds. Yet the doctors refused to declare that she was "terminal."

Such designation is also the criteria for hospice admission, and the average length of stay in hospice care is about two weeks, including some who've been in for a year or more. Many die within a few days of admission. Doctors and patients are reluctant to admit the reality. Moreover, by the time the terminal aspect is proclaimed, one nearly has a foot in the grave—the patient is very severely ill.

One doctor wrote this: "For years, I practiced in a state where, if someone thought you were administering too much pain medication to a terminally ill patient and the patient died, you could be charged with and possibly convicted of murder. No amount of suffering was felt justified to intervene with 'natural' death."

I personally have never met an individual who truly believed this on a rational, reasoned basis. In those who have professed this conviction, once the superficial logic had been taken away, it was always, at root, based on religious conviction. As such it has always been impervious to true discussion.

I fully respect the right of individuals to their own beliefs and end-of-life wishes. I do not condone the imposition of personal religious beliefs on someone who does not share the same convictions. *I believe it to be morally, ethically, humanely, and mercifully unconscionable that a dying person must accept prolonged suffering if that individual does not wish it. Yet this is the law in the vast majority of the United States.* And this is the official position of the American Medical Association. This sometimes is justified by the myth that physical and emotional suffering at the end of life can be controlled. We all know that this is often not possible. Sometimes we resort finally to medicating the individual into a semiconscious state. And just what is the point of that?

"This ignores the ability of people of intelligence and good will to write appropriate guidelines and laws to protect against such actions. Some of these people crafted the Oregon Death With Dignity Act."

Most, supposedly rational, reasons against assisted death are based on the "slippery slope" concept, that it opens the door to abuse and willful murder and then eventually to euthanasia. This ignores the ability of people of intelligence and good will to write appropriate guidelines and laws to protect against such actions. Some of these people crafted the Oregon Death With Dignity Act. In this act, passed by statewide vote in 1994 and re-passed and enacted in 1997, an adult Oregon state resident with a diagnosed illness confirmed by two physicians as likely to be terminal within 6 months, who is found to be

DIFFICULTIES *continued on page 15*

If Only I Had Known

By Janis Landis, President

John Greenleaf Whittier wrote: "For all sad words of tongue and pen, the saddest are these, 'It might have been.'"

From my perspective, an equally sad statement is "if only I had known."

At speaking engagements, as well as informal social events with friends, people hear about the work of FEN and say "if only I known my about your organization, my (friend, spouse, parent, etc.) would not have suffered so horribly."

And "if only" doesn't necessarily mean that the loved one would have hastened their end. It might simply be the relief provided by knowing there is a choice. Or by knowing that one can push back against aggressive treatment and seek more palliative care. It's about having permission to say No to needless suffering.

One individual spoke bitterly about the pointless physical rehab that was given to her frail terminally ill aunt, though it was clear she hated it and it was accomplishing nothing. Somehow, it seemed wrong to suggest to the staff that nothing should be done. She didn't fully understand that being an advocate for her aunt might mean protecting her from useless intervention. If she had only known...

Still another regretted the endless loop of hospital > nursing home > hospital trips her spouse suffered. Each infection was treated aggressively and painfully, although all that was accomplished was a few extra weeks with no improvement in quality of life (and a large financial hit). If only she had known…

A friend of mine recently said that after speaking to a FEN counselor, she was much better prepared to respond to a delegation of doctors who showed up in the room of her terminally ill husband. They informed her that they would be taking certain aggressive measures. She informed them they would be stepping out of the room so that she could consult with family and inform the doctors of her decision. After a period of reflection and family input, she decided against further measures. Her husband died peacefully a few days later. Although a highly educated professional in her own field, my friend said without FEN she would not have been emotionally prepared to respond so effectively.

FEN can help ensure that both the patient and the family understand their rights and are able to effectively communicate their end of life wishes.

And now you know.

Please keep us in mind for your year-end giving.

Our once-a-year appeal will be in the mail soon. Please open it and give. We only ask for donations once a year, so please respond when you receive your Appeal.

The Right to Die: Who Decides?

By Leonard Bernstein, DMD, MPH, BSc, Dipl. ABO, FACD. FAIDS

This is a condensed version of a presentation given by Dr. Bernstein.

Who decides about your own dying, a family member's dying, or the dying of a patient, especially a terminally ill patient?

There are many variables to consider, but I believe it should be a decision of the sufferer and not dictated by a political entity. And this right should not be limited to terminally ill patients who are mentally competent. It should be extended to allow assistance for those incapable of taking medications themselves, to allow the "mentally incompetent" to be included in those permitted to have their lives terminated, to allow the mentally "competent" but without a terminal disease to terminate their lives, and to allow children with terminal diseases the right to have their lives concluded.

"The right to die and dying with dignity is a societal issue, not a medical issue..."

Historically, as societies developed in size and complexity, and as medicine developed in scope and complexity, by default, physicians were handed over the power to dispense medications. Included in this arsenal of medications were those that could result in death. So, with the rise of concepts and acceptance of legal avenues to terminate life, the default mode for control fell to physicians, not only to dispense these terminal medications, but to be directly involved in deciding who was eligible to receive them.

For a variety of reasons, physicians were, and are, uncomfortable with this role society has thrust upon them and some refuse to take part in the process.

A Letter to the Editor of the Caribbean Medical Journal, written by a group of four individuals ranging from a doctor of medicine to a doctor of veterinary medicine, identified three pillars of medical ethics:

(1.) Autonomy, and specifically the ability of patients to have a voice in their own treatments. This autonomy should extend by default to the patient in the decision to terminate his or her life.

(2.) Justice, as it applies to the legalization of assisted death. Legislation embodied in statutes will permit both those granted the ability to allow for the termination of life and those seeking to employ those statutes the comfort of knowing they can decrease potential suffering by providing a safe means to terminate their lives.

(3.) Beneficence, to the extent of preventing pain and suffering to both patients and loved ones, mental and physical to patients and mental to loved ones. They opine that by legalizing assisted-death, patients can be provided with the opportunity of a dignified passing. My preferred term would be a *dignicide*, distinguishing it from *suicide* which suggests less rational consideration and usually a less peaceful procedure.

I submit (my thesis #1) that not to allow people to either terminate their lives or have professional assistance to end their lives constitutes, in the words of the United States constitution, "cruel and unusual punishment."

WHO DECIDES *continued on page 14*

A RIGHT-TO-DIE FILM FESTIVAL

By Faye Girsh, Ed.D., President, Hemlock Society of San Diego

It's not really a "festival" but we do have free showings of films related to dying every other month and have had for about 8 years. These films look at many aspects of dying. They come from everywhere—France, Italy, Spain, India, Japan, Canada, and the U.S.

Here's one you probably haven't seen: Bette Davis and Jimmy Stewart in **Right of Way** (a 2003 TV movie.) They're an "older" couple who have a modest, relaxed, funky life style. She (Bette) is diagnosed with a terminal illness. They decide they will die together, though he is in good health. They inform their daughter who drives down frantically to talk them out of it. When she is asked to leave their home because she is so insistent, she calls something like Elder Abuse services who eventually come around, note that there are cats and books all over the place and that the couple is determined to do this "double exit." When it seems like this devoted pair is about to be carted off to a "safe place for their own protection" they go into their garage, turn on the gas, and wait together. The daughter arrives, sees the garage closed, hears the motor running, and …What does she do? This is a funny and provocative, rarely seen film exploring some thorny issues.

But dying the way you want is an international problem. Another funny/serious movie is a 2014 Israeli film, **The Farewell Party,** about residents in a retirement community who know one of their friends is dying a difficult death and would like to end it. They connive to figure out a way, with the help of one of the residents who's a veterinarian. They are so successful that word spreads and their team is in demand. One of the team members has a wife with dementia who shows up at the dining room without her clothes on. She is mortified but, in sympathy, they have a surprise party for her where they're all clothesless. She and her husband eventually ask the group for help to die since her dementia is seriously interfering with her quality of life. They agree. This film raises the question of do-it-yourself methods, what does happen to people who die in old age homes, and the question of how to die when dementia has struck. It is a delight—and a shock if you've never seen nude old people.

Another, this one from India: **Guzzarish**, 2010. This is a beautiful film; the main characters are attractive young people in colorful clothes in an elegant house/mansion in Goa. He, a former actor who became a quadriplegic in an accident while shooting a film, she is his caregiver who, of course, loves him and agrees with his wish to die. They, with his mother and a lawyer, take his case to the courts but—as would happen here—his plea is denied. He has a radio program and explains his problem to his doting audience who also agrees. The end is a Bollywood-like party where the couple marry and she promises to help him achieve his wish. BTW, the issues for a quadriplegic to want an end to his life are also depicted in **A Sea Inside** with Javier Barden and **You Before Me** with Sam Claflin. Both men, rich, young and handsome, express their frustration at being in this situation and want to die. Their dilemma is reminiscent of that of Christopher Reeve who did die, but, presumably, not by his own hand. Though the disability community is often opposed to assisted dying for disabled persons, these three portrayals give an intimate idea of what life is like in a state of complete dependency.

Check out our web page at hemlocksocietysandiego.org for more information on our Film Festival. The discussions following these films are always full of questions and an excellent exchange of ideas.

COMMENTARY

It Takes a Worried Man to Sing a Worried Song

By Jerry Metz, M.D.

My friend Rick and I entered a Central American country illegally. We were hitching a ride down a dark highway in a Russian-made jalopy and, because I am tall I was sitting in the passenger seat. A little yellow light suddenly blinked briefly from the left end of the dashboard, and as time went by it stayed on. I guessed it was a primitive sort of fuel gauge and asked the driver, who confirmed my hunch.

"What did he say?" asked Rick, who didn't speak the language.

"He says we're low on gas."

"Well tell him to stop at the nearest gas station and fill up!"

Rick sounded nervous. I relayed the message and the driver laughed and made it clear the "nearest" was ten miles away. Rick's Spanish was adequate for this and his anxiety boiled over in a flash.

"Here we are at night in this damned country with no map, no compass, not even a flashlight and we're running out of gas! Ask him: isn't he worried?"

I asked. The driver's teeth flashed in the dim light as he smiled, shook his head, and gave us the difference between Central American and gringo mentality: "I'm not worried. Worried is what you do when you *run out of gas*."

Amen, brother.

Some terminally ill patients show remarkable equanimity. A few are worried enough to seek assurance, even applying for assignment of Exit Guides to accompany them through their last moments, to be their map, compass, and light at the end. Guides are only assigned after the Medical Evaluation Committee gives approval. Approval is not likely no matter how dire the diagnosis if the patient is comfortable except for anxiety, which is not a terminal illness. If the disease were to take an ugly turn the Network is nimble and can extend compassionate coverage very quickly.

My message is simple: Do not let worry cloud your last days, but live with as much love and appreciation as you can muster, secure in the knowledge that if events push you into a decision to "take early retirement," the caring and expertise of the entire Network will be yours. ■

COURAGEOUS TEST OF A NEW METHOD OF SELF-DELIVERANCE

The research group NuTech, which investigates various methods of self-deliverance, is studying a new method based on a commonly available inorganic salt. Although the substance has long been known to cause severe physiological effects which can be fatal, only recently has it been considered as a possible "peaceful pill" for hastening death. This lack of interest may have been because if a sublethal dose is ingested, the effects are far from peaceful, with adverse symptoms including nausea and abdominal cramping. However, close study of the medical literature suggests that high doses may lead to unconsciousness and death quickly, before adverse symptoms appear, suggesting that this substance may be useful for a peaceful self-deliverance.

In May of this year, Juanita Ainsley, a longtime FEN volunteer in failing health, chose to hasten her death using this untried method, and, heroically, to publicly share her private choice so that the death with dignity community could learn from her experience. She studied the risks and advantages of the method, and procured the salt, a common food preservative. Through her research, she felt comfortable following the protocol suggested in Philip Nitschke's *Peaceful Pill Handbook*. Because she wanted knowledgeable people to be present as witnesses and to document the event, she applied and was accepted into the Exit Guide Program. Hers would be the first monitored, rigorously planned self-deliver-

ance using this substance, and she approached her choice with care and attention. Juanita was very familiar with the inert gas method and could have chosen to use it. Instead, she elected to have her inert gas equipment available, at her side, to deploy if she experienced unpleasant symptoms.

Juanita's self-hastened death was reported as peaceful. Several minutes after drinking the salt dissolved in water, she slipped into unconsciousness, apparently experiencing little discomfort. Her vital signs ceased within the hour. This result is consistent with the most optimistic expectation based on the limited information gleaned from medical journal reports.

The observations made possible by Juanita's courageous choice were shared with NuTech and could lead to an exciting development in right-to-die history, offering the possibility of a new method that would be more readily available, less expensive, less physically demanding, and perhaps more dignified than the inert gas method. Nevertheless, there remain obstacles, including the likely variability of physical effects of the salt from one individual to another, and the uncertainty whether suitable volunteers will offer their participation as subjects. Further developments will be reported as they evolve.

An excerpt from one of Juanita's paintings featured in our last issue.

COMMENTARY

How Did a Nice Girl Like You...?

By Judith Hinds

I volunteer with Final Exit Network. How the heck, people ask, did I get involved in that.

My mother fell and broke her hip at age 94. Though still lucid and making her own decisions, she leaned heavily on my opinion. The orthopedist told us that if Mom didn't have hip-replacement surgery, she would be bedridden and uncomfortable for the rest of her days. Surgery would be her best shot at walking again. We consented.

Like many other elderly hip candidates (I learned later), Mom was never herself after the surgery. The anesthesia and/or the whole trauma clouded her mind. Rehab failed to help her regain her balance. She couldn't understand why "they" wouldn't let her go back to her beloved sunny-yellow room in the assisted-living residence. Why did she have to stay in this smelly nursing home with crummy food and ugly wallpaper?

Seven months post-surgery, demented and miserable, she caught an upper respiratory infection. Her assigned doctor prescribed antibiotics. I asked why. Wasn't she ready for hospice care yet? He said sure, he could request hospice. I had been waiting for him to suggest it; he had been waiting for me to ask. She was so agitated by then that hospice prescribed a Fentanyl patch. She turned her head away from food and water and slipped into a coma. Three days later, her spirit was freed to do whatever spirits do when they're finally released from their physical prisons.

I'll never know whether surgery was the right decision, or what might have been different if I'd asked about hospice six months sooner. But I knew for sure that I didn't want to end up in Mom's situation. I'd heard of the Hemlock Society years earlier, so I Googled it. The search led directly to Final Exit Network. I joined. In 2014, the newsletter announced a need and a training opportunity for exit guides. Yes, I said. I could do that.

Because my travel radius is self-limited, I've only had one chance so far to serve as an associate guide. That experience–a peaceful exit of a client holding hands with her husband and sister–convinced me that this work is for me. Our clients are such thoughtful, searching, reflective people. Serving as a phone coordinator allows me to provide them with the information and reassurance they need to walk the path to their chosen end. It is really a privilege to be invited into their lives, however briefly. I hope I have their clarity and courage when my time comes to choose.

Good Endings Book Club

Seven Ways of Looking at Pointless Suffering by Scott Samuelson

Reviewed by Huck DeVenzio

Foolishly judging a book by its cover, I figured that a volume with the title above must focus on positive and negative aspects of suffering with regard to death with dignity. I was off by a half-mile. This book spends more time on Charlie Chaplin, blues music, and Elmer Fudd than it does on hastened death, and far more time on the U.S. corrections system.

The author reviews writings by several renowned philosophers—among them John Stuart Mill, Friedrich Nietzsche, Hannah Arendt, and Confucius—and recommends that people both accept and reject suffering. He sees value in suffering, including artistic inspiration, and says "Evil is fundamentally a mystery rather than a problem" and "Great thinkers from various backgrounds understand that suffering is integral to human growth."

I am not a fan of suffering, pointless or otherwise, and I don't particularly like discussions of philosophical thought, so after the title this book was heavy going for me.

Checking Out of the Hotel Euthanasia by Gerard Graham

Reviewed by Gini Rainey

Here is a very interesting read that reveals a lot about human nature in a very satirical format. Graham spins a tale about a fictitious hotel in the fictitious kingdom of Villadedino that had pretty much fallen to ruin when Zeca, a hotel manager, was appointed to the most prestigious hotel management spot in the world. Because of Zeca's capable management, the once decaying hotel, rose from the ashes to become a mecca for those seeking assisted dying.

On the other side of this coin is Rab and a small group of cohorts who are on a Pope-funded mission to destroy the hotel because of the Catholic anti-assisted death platform.

Rab, who once supported assisted-suicide with a great passion, now has turned those passions against the Hotel Euthanasia and all that it represents and assumes his leadership role with great vigor.

Along the way, we are introduced to people from various walks of life who are guests at the Hotel and are seeking release from their earthly bodies in one of the various ways offered by the Hotel. The back stories of these people could be novels in themselves but, bound together, they comprise a very interesting read filled with different ways to look at euthanasia. And while some readers might find the whole concept exceptionally macabre, the idea behind it certainly carries merit for those facing a lifetime of pain (however long) and an eventual death.

Correction

In the conference program and May/June newsletter we misspelled the name of Jürgen Dankwort. We apologize, and know that he probably would not have misspelled ours—he holds a PhD from the University of Montreal and an MSW from McGill University.

WHO DECIDES *continued from page 10*

The right to die and dying with dignity is a societal issue (thesis #2), not a medical issue, and as a societal issue is a public health issue. Physicians should not be the state's agent to provide life- ending medications. The state should license, and allow the training, of public health officials, and which may include physicians who prescribe medications to terminate a life.

Every state, country or similar legal jurisdiction should allow those residing within its borders (thesis #3) the right to die and to die with dignity with laws not unduly interfering with these rights.

I have presented information, evidence and argument supporting the concept of a right to die and for dying with dignity. Ultimately, decisions in these regards are yours. I therefore leave you with the question: *What do you want for yourselves and for your loved ones?*

SCENES FROM THE ANNUAL MEMBERS MEETING 2018

Board members and guests met in Chicago in August for the Final Exit Network Annual Membership and Board meeting.

DIFFICULTIES *continued from page 8*

mentally competent and not significantly depressed, may be written a prescription for a lethal amount of an oral medication, which must be self-administered.

Some California hospitals have opted out of participating, claiming they cannot tell when someone will die. This is a specious argument if I ever heard one, since physicians have been pronouncing people "terminally ill" for decades as criteria for hospice admission.

And there is a new front in the battle against death with dignity. Opponents are seeking to stop the laws in state courts after years ago losing federal court cases filed in Oregon and Washington. Now they are moving into state courts in California and Vermont, hoping they will get a different result. Make no mistake: The doctors and the anti-choice groups funding these lawsuits are political operatives attempting to derail the laws any way they can.

For the right to die, requiring that one must be terminally ill is a severe restriction and prohibits PAD (Physician Aid in Dying) from going far enough. By including this criterion, PAD laws exclude many who may wish to hasten their deaths due to hopeless and interminable suffering experienced far in advance of being labeled "terminal," such as those with early stage Alzheimer's disease, progressive disorders such as ALS or MS, and other illnesses. Those with dementia may have to wait until it is too late, being judged as incompetent to give informed consent for PAD.

2. PAD is expensive.

The lethal prescription can cost several thousands of dollars, usually not paid for by insurance. The Final Exit Network method costs about $300.

3. Even in states like Oregon, where PAD has been legal for decades, it is not that easy to find a physician who will comply.

Many doctors and hospitals will not participate because of disagreement based largely on religious beliefs.

It would be best if we were to terminate the "terminal" aspect of such laws. There is a group in Oregon working on doing just that with the assistance of Derek Humphry.

Mr. Abraham is an author (notably, How to Get the Death You Want*), retired Episcopal priest, thanatologist, and member of FEN.*

FINAL EXIT NETWORK
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