

FINALEXIT™ NETWORK NEWSLETTER

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SUPPORTING THE HUMAN RIGHT TO A DEATH WITH DIGNITY

www.finalexitnetwork.org

“Let’s
Talk
About
Death”

Self-Deliverance and Bridge Traffic

By Jim Van Buskirk

I first met M over two years ago while holding open the side door of the Potrero Branch Library. The tiny woman was walking her dog down 20th Street and noticed my T-shirt, which read “Let’s Talk About Death.” What’s going on here, she wanted to know. When I told her that we were about to convene a Death Café, she immediately asked if she could attend, and her little dog too.

I have been co-hosting Death Cafés for over two years, as well as reading voraciously, watching documentaries, and speaking to anyone and everyone about this taboo topic. Not that I consider myself an expert by any means, but as I become more comfortable I am on a crusade to help others deal with their cultural discomfort about our common destination.

Perhaps that’s why M invited me to accompany her on the next leg of her journey. A few weeks ago, she called to say she’d contacted the Final Exit Network and asked me if I would be there with her when the volunteers guided her through what they refer to as “self-deliverance.” I immediately said yes, not knowing what this would entail or whether I was up to the task, and yet knowing

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Our apologies for the tardiness of our Winter issue. We have been preoccupied with arrangements for the Dying in the Americas 2018 conference.

that this was the next step in my learning curve. M was delighted and I was honored. And nervous.

I didn't know M well, but gradually learned that the 88-year old had been a renowned Jungian therapist, author, and workshop leader. Still brilliant and brainy she was intense, yet so soft-spoken that many Death Café attendees could scarcely hear her voice over the whir of the fans that kept the air circulating in the library's small meeting room. Over many months, M enthralled, educated, and perplexed many of us with her talk of patterns, the importance of this group in her life, and her frustration with her slowly diminishing capacities to drive, to see, and eventually—she feared—to think.

Astonishingly, she continued to attend regularly, even after moving from Wisconsin Street house



not parked in the facility's garage and only feigned signing in. M had originally offered to give me a sculpture by a well-known local artist, but I didn't feel comfortable being seen leaving her apartment carrying artwork. Instead, knowing I was a librarian and a writer, she handed me a box with the complete set of her published books.

While we chatted, M was amused that she repeatedly forgot the word that came after Final.

where she'd lived for over forty-five years to a senior community residence across the bay in Oakland.

"I don't like it 'over there,'" she'd said dismissively. "I hate that I have to go back to the other side."

"You make it sound like you're crossing the River Styx," I teased her.

"I might as well be," she agreed, before getting herself to a BART Station to return to her new living quarters.

After I agreed to witness M's departure, I spoke to the Final Exit Network volunteers by phone. I was immediately calmed by their sense of purpose. They explained the process and assured me that self-deliverance was not illegal, quelling my anxiety about any legal liability. I didn't much like the term "self-deliverance," only slightly preferable to "suicide."

After several phone calls and emails, we had a plan, and a date. I told a few friends what I was planning to do. One friend, a minister who'd witnessed at least 50 suicides, many during the AIDS pandemic, offered helpful advice on what to expect. His counsel was invaluable. What a beautiful day, I noted as I drove across the Bay Bridge.

M was simultaneously calm and keyed up as I entered her apartment. Taking a friend's advice, I had

Now she was most concerned about a big wicker basket of cat food, treats, and toys. She'd managed to get her cat to its new home that very morning, but had forgotten its food. I agreed to drop off the basket, assuring her I'd call the friend, one less thing for M to take care of. While we chatted, M was amused that she repeatedly forgot the word that came after Final. When I supplied it for her, she remarked with a rueful smile, "Isn't it funny, that's the word that I can't remember?"

The FEN volunteers arrived precisely at 2:30 as planned and I marveled at how patient, knowledgeable, and personable they both were. Because M could scarcely see, I read out the checklist of items, while M impatiently agreed to each one. She articulated why she was intent on self-deliverance, reiterated that she knew exactly what she was doing, and was eager to carry out her task. We watched as she signed the document with determination. The volunteers then showed her how to assemble the equipment she'd ordered, instructing her step-by-step. Despite her requests, they repeatedly declined to actually do anything for her, insisting that she accomplish each task herself. With persistence and a bit of frustration

BRIDGE *continued on page 4*



One family's experience with Dignitas: My Terminally Ill Aunt Wanted to Die on her own Terms, but Couldn't.

In an article with the above headline, posted in August on *BuzzFeed*, journalist Luisa Rollenhagen tells the unfortunate story of her aunt's death without dignity, despite good intentions and reasonable preparation. An introductory sentence sums it up: "When [my aunt] was diagnosed with terminal cancer, she asked me to help her get to Switzerland, where assisted dying is legal—but we had no idea how many complications would stand in our way."

For the Argentine aunt and her niece, it seemed as if it would be straightforward: Should death be imminent, she could avoid an undesirable ending on her own terms by traveling to Switzerland with assistance from the respected Swiss organization, Dignitas. She had written this into her will.

The stylish, independent aunt had no desire to "die slowly and decrepitly, with adult diapers and dribbling spittle." So, when told that she had an aggressive pancreatic cancer, she asked her niece for help with arrangements.

Though medical-aid-in-dying is permissible in Switzerland, Dignitas abides by reg-

ulations to protect itself. They required PET scans, the biopsy report, and oncology reports—all originals. As this paperwork was collected, mailed, and processed, the aunt's condition steadily worsened, as did her frustration. Then came requests for a birth certificate, marriage license, and divorce papers. Gathering some of the reports required bribes to government officials to speed their effort.

The family did not get to the point of seeing Swiss doctors for the necessary sign-offs. By the time all else was ready, the aunt was no longer able to handle the long flight to Europe. Her plans and wishes had to be scrapped. She died in the way she hoped to avoid.

Apparently the Dignitas procedures are complex and cumbersome—for the sake of the patient and the preservation of the orga-

*Gathering some of the
reports required bribes
to government officials
to speed their effort.*

nization. FEN has similar concerns but, from this account, FEN's requirements may be less onerous. And, at least within the United States, there are fewer travel problems since FEN volunteers do the traveling (paid by members' dues, donations, and bequests) rather than the applicants making and financing trips.

With both organizations it is important that an applicant not wait until he or she is unable physically or mentally to carry out the plan. Once that occurs, there is no legal option. ■

A LETTER FROM A PATIENT'S DAUGHTER

By Elisabeth Hansot

...As I think back on it, I am astounded that I had so little inkling of how hard it would be to help my mother have the death she wanted...I tried to accompany her into the intensive care unit but could not...An hour later, when I was allowed to see her, she was attached to a respirator and had a feeding tube inserted down her throat. What had happened?...Exactly the opposite of what she had wished had occurred; the living will had become invisible just when it was needed most...I found that I was dealing with a bewildering array of medical specialists trained to prolong lives, not to let patients die...My mother's wishes, as they were understood by her family physician and her daughter, were now subject to the approval of strangers: the cadre of cardiologists, neurologists, and pulmonologists who attended her. None of these specialists knew my mother, and they all had their convictions about how to do best by her... ■

BRIDGE *continued from page 2*

she assembled the hood, taping the plastic tube inside and securing the bottom with a headband. She connected the other end of the tube to the regulator which she'd screwed onto the canister. The volunteers emphasized that it might not be elegant, but it would be effective.

In the middle of the proceedings, the phone rang and M automatically, without thinking, answered it. The three of us rolled our eyes as we listened to one-half of a very long-winded conversation involving \$11 which M promised to put in an envelope tomorrow. Don't let me answer the phone again, she requested after hanging up. The poignancy of the fact that there would not be a tomorrow was not lost on any of us.

After M finished the sequence of tasks, she was asked again if she knew what would happen if she continued, if she wanted to change her mind, if she wanted to take a break. Adamantly: yes, no, and no.

"Jim will be driving back across the bridge and there'll be traffic later."

I tried to explain that I was here for the duration and not to worry about my traffic, but she remained focused on the details as well as the big picture. I was impressed and inspired by her resolve.

Once she decided where she wanted the event to

take place, on a daybed with a sunny view of the bay, all was ready. After the brief demonstration, the volunteers explained that M would lose consciousness in about a minute and that the entire process would take less than fifteen minutes. Again, the three questions, again the impatient reply. With no ceremony or final words, the three of us watched as M turned the dial, pulled down the hood, and began inhaling.

She closed her eyes as her breathing became shallow. One of the volunteers monitored her pulse. A few physical twitches and soon she was gone. She looked peaceful. It had been so sweet, simple, sad, and straightforward. I was moved by the simultaneously monumental and mundane moment of what we had witnessed.

We removed the hood and disconnected the canister, packing everything up to carry out of the apartment. It was far less conspicuous than the big basket of cat paraphernalia I carried. Since the equipment couldn't be taken back on the flight, the volunteers were planning to jettison it. When they offered it to me I accepted. As we shook hands, I realized what an important service they, we, had provided.

After weeks of careful preparation, the entire process took less than two hours from start to finish.

I drove across the bridge—no traffic—and immediately joined Final Exit Network. ■



The Ultimate Cruise

By Jerry Metz, MD

“The doctor seemed unaware that there is a darker side to the coin of medical capabilities.”

Modern medicine is like a sailboat. It carries the ancient mariner slowly and at great expense and discomfort in a direction he does not particularly want to go and expects him to enjoy the ride.

My recent trip to the doctor revealed the extent to which a normal decline of age has been medicalized. The doctor seemed delighted to have sighted early indications of storm clouds on the horizon and exhibited her knowledge by listing a series of elaborate high-tech tests that would surely reveal the intensity of the impending torment so we could reef the sails in time to avoid a knockdown.

There is a difference between knowledge and wisdom. The doctor seemed unaware that there is a darker side to the coin of medical capa-

bilities, such that self-congratulatory comments about someone else's diagnosis do not cushion the negative impact of that news to the patient. Less obvious is the unspoken assumption behind the whole charade: It is simply taken for granted that all patients seek to live as long as possible and will suffer whatever is demanded in order to flee the guy in the sheet carrying a long scythe, forgetting that we can run but we cannot hide.

By the bedsides of terminally-ill patients about to intentionally end their lives I have been impressed by the calm courage they have shown: a positive emotion, far from mere acceptance. They were some of the most grateful patients I ever met, pleased to be able to steer their boats home, avoiding a shipwreck at sea.

Longevity can be a blessing or a curse. Be careful what you wish for. ■

Choosing a Healthcare Facility to Optimize Options

Suppose you are about to enter a hospital for a serious procedure, or you think it would be best to move into a retirement village or nursing home, and you want to choose a facility that will honor your living will or DNR instructions or your desire for a peaceful exit. How can you verify that a facility will accommodate your wishes?

Even in states that allow physician-aided dying (PAD), you can't be sure your desires will be followed. Their reason may be inadvertent (ignorance of your desires or standard emergency practices) or they could be intentional institutional policy. Faye Girsh notes that in California, which permits PAD, Catholic facilities will not currently permit PAD or Voluntary Stoppage of Eating and Drinking (VSED). Neither will most hospitals.

She continues, "...once you're in Assisted Living or Skilled Nursing, or a Memory Unit, life is pretty much controlled. Visiting someone there or working with a tank is not a good solution. Even in Independent Living there is some degree of scrutiny. Going to a family home or a friend's home (or a hotel with someone) is possible (but traceable). Very tough situation."

So what can you do?

"If I felt that my medical conditions were such that I MIGHT want to exit some time in the next 18 months," said veteran advisor Ann Mandelstamm, "and if I were living in my own home, condo, apartment, or mobile home at the time, I would not seriously consider moving any other place. This is because setting an 18-month window would not postpone indefinitely a move to a place where I could get more care, when needed, but would focus my attention on the next 12 to 18 months. This is based on my experience, not scientific data.

"If I were already in a senior apartment building with assisted living facilities on site or very nearby, I would not move to the assisted living facilities until I had worked out in my mind a strategy for self-delivering in the somewhat near future. The reason is that in every situation I can think of, ending my life with

DON'T TELL JOHN MCCAIN TO FIGHT HIS CANCER

By Arthur L. Caplan, PhD

Excerpted from Medscape (WebMD),

July 25, 2017

*People Mean Well,
But It's the Wrong Tactic*

Here is a sample from Twitter. Barack Obama said, "John McCain is an American hero, and one of the bravest fighters I've ever known. Cancer doesn't know what it's up against. Give it hell, John." Joe Biden: "He is strong, and he will beat this."

Gabrielle Giffords: "You're tough! You can beat this. Fight, fight, fight!" Mike Pence: "Cancer picked on the wrong guy. John McCain is a fighter, and he'll win this fight too." A bunch of editorials in many newspapers across the nation echoed similar thoughts.

This is advice McCain does not need.

The odds of beating this cancer are long. Whether he does or doesn't has nothing to do with his character or courage.

Whatever cancer does to John McCain and however he chooses to treat it or not, he is a brave man who is certainly a fighter. As with anyone, he will find his own best path to dealing with a grim diagnosis. Whatever that is, he will remain a hero and a fighter. ■

the support of FEN or some other means would always be easier and safer for me in a place where there was less supervision, not more. My goals would be to end my life on my own terms and not to jeopardize anyone's legal or physical safety."

Mandelstamm related a specific case. "I am aware of a person who lived in an independent apartment in a senior residence, but due to physical disabilities could not self-deliver there. This person planned to go to an adult child's residence for that, and the family was in total agreement. They knew the risks and were willing to assume them. So it can be done, no matter how disabled a person is or how risky the physical setting might be—IF the family is willing to assume responsibility. That is a big IF, but

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DO NOT RESUSCITATE

An Unconscious Patient With a DNR Tattoo

The following letter was written to the New England Journal of Medicine by Drs. Gregory E. Holt, Bianca Sarmento, Daniel Kett, and Kenneth W. Goodman. At first glance, a tattoo would seem to be a foolproof indication of a person's wishes, but legally and ethically it is not so clearcut. Doctors cannot be certain that a tattooed message reflects its bearer's current feelings. One man with a DNR tattoo told doctors that he got his tattoo because he had lost a poker bet. Newsweek coverage of this story included a quote from Arthur Caplan, a professor of bioethics: "If you trigger the emergency response system, I'm going to say it's pretty darn likely you're going to get resuscitated—I don't care where your tattoo is."

We present the case of a person whose presumed code-status preference led him to tattoo "Do Not Resuscitate" on his chest. Paramedics brought an unconscious 70-year-old man with a history of chronic obstructive pulmonary disease, diabetes mellitus, and atrial fibrillation to the emergency department, where he was found to have an elevated blood alcohol level. The staff of the medical intensive care unit evaluated him several hours later when hypotension and an anion-gap metabolic acidosis with a pH of 6.81 developed. His anterior chest had a tattoo that read "Do Not Resuscitate," accompanied by his presumed

signature. Because he presented without identification or family, the social work department was called to assist in contacting next of kin. All efforts at treating reversible causes of his decreased level of consciousness failed to produce a mental status adequate for discussing goals of care.

We initially decided not to honor the tattoo, invoking the principle of not choosing an irreversible path when faced with uncertainty. This decision left us conflicted owing to the patient's extraordinary effort to make his presumed advance directive known; therefore, an ethics consultation was requested. He was placed on empirical antibiotics, received intravenous fluid resuscitation and vasopressors, and was treated with bilevel positive airway pressure.

After reviewing the patient's case, the ethics consultants advised us to honor the patient's do not resuscitate (DNR) tattoo. They suggested that it was most reasonable to infer that the tattoo expressed an authentic preference, that what might be seen as caution could also be seen as standing on ceremony, and that the law is sometimes not nimble enough to support patient-centered care and respect for patients' best interests. A DNR order was written. Subsequently, the social work department obtained a copy of his Florida Department of Health "out-of-hospital" DNR order, which was consistent with the tattoo. The patient's clinical

**"This patient's
tattooed DNR
request produced
more confusion
than clarity . . ."**

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The Ambiguity of Life Support

By Sharon R. Kaufman

Following is excerpted from “...And a Time to Die,” a book subtitled “How American Hospitals Shape the End of Life,” based on in-depth interviews with physicians, nurses, administrators, patients, and families.

Life support is a central fact of critical illness in today’s hospital world...Life support refers both to specific medical procedures and to the various interpretations of those procedures. The term life support per se is never used in daily hospital practice, and health professionals do not use it at all. Rather, it is a term that circulates in public talk, especially to refer to what many say they do not want if it will only prolong dying.

Newspaper opinion pieces, popular books about personal control over dying, and organizations that promote dialogue and change in end-of-life medical care would have it that the technology-driven American hospital system is the primary culprit in the problem of prolonging dying unnecessarily because it promotes the use of “unwanted” life-sustaining measures. Patient (and thus family) “suffering” is considered by many, both within and outside of medicine, to be a direct result of “overly aggressive” life support procedures. Yet physicians (even as they struggle to work autonomously within hospital bureaucracies, are very aware of the social criticism directed toward them) repeatedly gave me a different perspective. On the contrary, they said, it is families who do not want

to and cannot “let go” of their relatives and want to keep them on life support past (sometimes long past) the time when there is a life to support. Over time, I observed both groups to be right and both to be culpable. In some instances, hospital staff and families, in about equal proportion, wanted to pursue life-sustaining treatments in the hope that the patient, the person, would be restored to some level of function. In other instances, both groups intervened in equal numbers to stop the domination of the heroic pathway. And sometimes, ambivalence, silence, or evasion reigned and neither doctors nor families pressed hard for life-supporting measures or their withdrawal. Regardless of who tries to stop the course of life-sustaining, death-defying treatments, which treatments are stopped or avoided, when treatments are stopped or whether they are stopped at all, life support is a mutable phenomenon, always linked to the politics and rhetoric of the patient’s condition.

The contingent nature of life support was first made evident to me when, eventually, I questioned an experienced critical care nurse about it. Our conversation began when I commented that the mechanical ventilator seemed to me to be the only obvious life support technology. She replied, “I think at some point in time the mechanical ventilator can be life support. I don’t believe that all the time it is. But let me clarify that a little bit. The patient with pneumonia comes in. And that is the only thing he’s got, pneumonia. But

AMBIGUITY continued on page 14

Picking when to die: A right or a wrong?

*The Press-Republican,
Plattsburgh, NY, Sept. 13, 2017*

Physician-assisted suicide is not going away as an issue in New York state. Nor should it. The state's highest court has ruled against terminally ill patients who want to be able to end their lives as comfortably and quickly as possible. Ending one's own life is thus not legal in this state.


The argument—hardly a new one—therefore will likely transfer back to the legislature, which has not embraced the notion of doctor-assisted suicide in the past. This is an issue that should be vigorously debated in the public and get a fair and thorough hearing. Emotions run high on the topic, as proponents on both sides insist they are supported by right and reason.

Backers of enabled suicide say a person with the grim outlook for a long process of dying—mentally and perhaps even physically painfully—have no choice but to endure it. Some people simply cannot bear the thought of living for months or years with severe disability and beg to be allowed to end life with grace and dignity.

They note the fact that it's legal to take their pets to a veterinarian for a quick, painless euthanasia but not so with themselves. They ask: What could be a more precious right than to choose whether and when to die?

Those on the other side lean heavily on the tenets of religion for their justification. "Thou shalt not kill" means yourself, as well as others. They also note that opening the door to doctor-assisted suicide invites regrettable mistakes. Some of the people who choose when to die may not be of sound mind or could have missed opportunities for eventual relief from their miseries.

On the matter of physician-assisted suicide, a spirited public debate is the only way to reach any kind of conclusion. Minds will not change easily, if at all. The majority should rule. ■



*What could be a more precious
right than to choose whether
and when to die?*

The Good Death Society Blog

A Project of the Final Exit Network

AMERICAN ACADEMY OF NEUROLOGY DROPS OPPOSITION TO MEDICAL AID IN DYING

Mar 11, 2018, Thaddeus Mason Pope, JD, PhD

thegooddeathsocietyblog.net

For other insightful essays, visit the blog and subscribe.

The American Academy of Neurology (AAN) has dropped its longtime opposition to legislation giving terminally ill patients the option of medical aid in dying.

Medical aid in dying (MAiD) gives mentally capable, terminally ill individuals with a prognosis of six months or less to live the option to request, obtain and self-ingest medication to die peacefully in their sleep if their suffering becomes unbearable.

According to the AAN position paper, the decision “was influenced by the results of a 2014 AAN-sponsored Ethics, Law and Humanities Committee survey that suggested that a notable percentage of AAN members might feel bound by conscience to comply with the wishes of their dying patients for assistance in hastening death” (i.e., medical aid in dying).

The survey showed that more than 70 percent of responding members from states where medical aid in dying is authorized endorsed the practice of “lawful physician hastened death (LPHD) as an “ethically permissible behavior.” In addition, more than 50 percent of these same individuals reported that “they would be willing to assist their patients in hastened death.”

After deliberation of the Committee’s recommendations by the AAN Board of Directors, the AAN position paper states:

“...the AAN has decided to leave the decision of whether to practice or not to practice LPHD to the conscientious judgment of its members acting on behalf of their adult patients dying of neurologic illness.”

Medical aid in dying is authorized in seven U.S. jurisdictions whose collective population represents nearly one in five Americans:

California	Vermont
Colorado	Washington
Montana	Washington, DC
Oregon	

These seven jurisdictions have more than 40 years of combined experience of safely using this medical practice.

Numerous other medical and health groups have dropped their opposition to medical aid in dying and adopted a neutral position. They include:

American Academy of Hospice and Palliative Medicine
American Pharmacists Association
Oncology Nursing Association
California Medical Association
California Hospice and Palliative Care Association
Colorado Medical Society
Maine Medical Association
Maryland State Medical Society
Massachusetts Medical Society
Medical Society of the District of Columbia
Minnesota Medical Association
Missouri Hospice & Palliative Care Association
Nevada State Medical Association
Oregon Medical Association
Vermont Medical Society
Hospice and Palliative Care Council of Vermont
Washington State Psychological Association.

In addition, six national medical groups have endorsed medical aid in dying, including:

American College of Legal Medicine
American Medical Student Association
American Medical Women’s Association
American Nurses Association of California
American Public Health Association
GLMA: Healthcare Professionals Advancing
LGBT Equality
New York State Academy of Family Physicians. ■



Conscientious Objection: Can a hospital refuse to provide treatment?

By Claire Horner, J.D., M.A.

The following is an excerpt from an essay posted September 29, 2017 on the Baylor College of Medicine blog. Ms. Horner is an assistant professor in the Center for Medical Ethics and Health Policy.

Canada recently legalized medical assistance in dying (MAiD), which allows patients to receive a lethal drug that they can self-administer, or be administered a lethal drug by an authorized clinician with consent of the patient. As provinces and territories work to create and clarify legal guidelines for providing MAiD, many Catholic hospitals have refused to offer it, citing opposition to physician-assisted suicide and euthanasia in Catholic moral teaching.

This controversy surrounding institutional conscience-based refusals raises an important question: Should a health care institution have the right to refuse to provide a particular treatment for conscience-based reasons?

Conscientious objection, while often debated in bioethics and law, is a right widely recognized among healthcare providers. Individuals involved in patient care generally have the right to refuse to participate in procedures that violate their personal values, subject to certain restrictions such as availability of the patient to seek treatment elsewhere. But does an institution have the same right to refuse to provide services based on religion or ethics?

Opponents of institutional conscience-based restrictions argue that healthcare facilities that receive

public funds and provide services to the community should not be allowed to refuse to provide care that is otherwise legally available to a patient.

Proponents argue that religiously affiliated hospitals are filling a role that is otherwise not currently filled by a public or government institution, and if they are required to provide healthcare that is in opposition to their established ethical policies, they may decline to continue to provide healthcare services at all rather than compromise their religious and ethical tenets.

This would then place a significant burden on the government or other healthcare systems to fill the void that would be left without such

hospitals, further restricting available healthcare, particularly in rural areas with few, if any, healthcare facilities.

It is an open question whether palliative care is a sufficient substitute for MAiD for patients who request it, but from a Catholic perspective, it allows physicians to relieve a patient's pain without intending the patient's death. While the controversy surrounding institutional conscience-based objections is not likely to be resolved anytime soon, patient-centered care should still be the priority of all institutions. ■

"It is an open question whether palliative care is a sufficient substitute for MAiD for patients who request it . . ."

status deteriorated throughout the night, and he died without undergoing cardiopulmonary respiration or advanced airway management.

This patient's tattooed DNR request produced more confusion than clarity, given concerns about its legality and likely unfounded beliefs that tattoos might represent permanent reminders of regretted decisions made while the person was intoxicated. We were relieved to find his written DNR request, especially because a review of the literature identified a case report of a person whose DNR tattoo did not reflect his current wishes. Despite the well-known difficulties that patients have in making their end-of-life wishes known, this case report neither supports nor opposes the use of tattoos to express end-of-life wishes when the person is incapacitated. ■

AMBIGUITY *continued from page 8*

he's not breathing well from it and it's really compromising his respiratory status, so we intubate him. Is that ventilator at that point in time life support? In my opinion, no, that's an adjunct to his therapy to get him well.

"It truly is a very murky area, because my opinion of where life support starts for that person may be very different that where life support starts for someone else."

Next I asked her about kidney dialysis. "Again, I think it's in a similar category with the vasoactive medications and the ventilator. I think that sometimes it's a therapy that can help."

This critical care nurse defined life support by interpreting the relationships among actual disease processes, medical procedures, and the body's response to the diseases and the procedures.

...[S]eriously ill hospitalized patients whose bodily systems are being supported by various medical means often change their minds about which kinds of life support they would accept in the future. Some decide, contrary to their pre-illness claims, that ventilator support, if necessary for continued survival, would be acceptable given their present condition, though CPR would not be. Others draw the line differently, stating that dialysis is acceptable, or tube feeding, for example, but that mechanical ventilation is not. ■



Frequently Asked Questions from Our Members

By Judy Snyderman, Treasurer

How can I tell the date when my membership expires?

Check the line directly above your name on the NL address label. (Remember that for lifetime members no expiration date will appear.)

Does my membership in FEN automatically qualify me for the exit guide program?

(The member who wrote this did not specify whether the question is concerning as a guide or as a receiver of guide services, so we'll mention both.) Neither is "automatic." You have to qualify, and there is a fixed protocol for each. As a guide: You apply for the training weekend, which is held periodically. The head of the training program will send you all the details when a training is scheduled, usually in the summer for the October training. All members are sent an email when we have a call for new guides. As a possible receiver of guide services: Call us by phone and leave a request or contact us through the "Contact Us" button on the website. Please be sure to leave the reason for your call, your phone number, and the

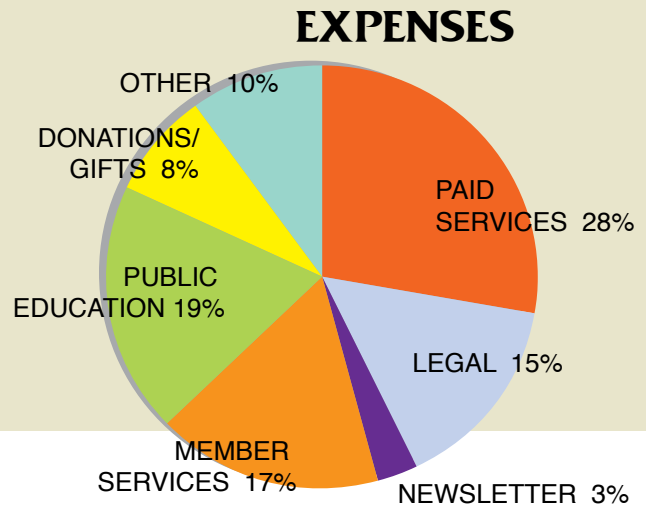
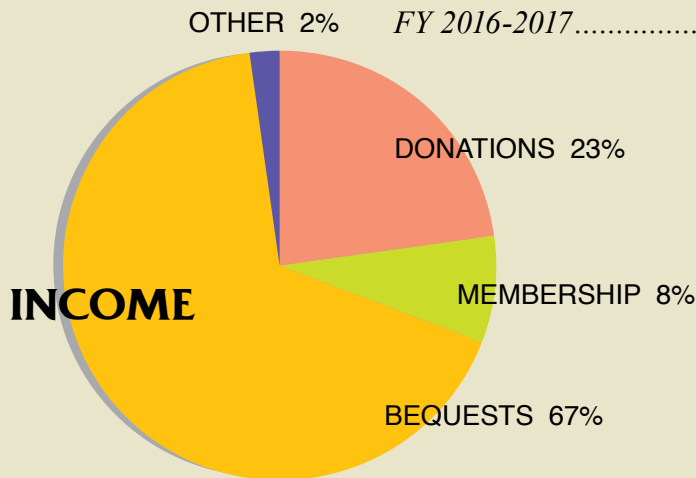
Financial Statistics for Past Fiscal Year

Total Income - \$1,458,507 Total Expenses - \$653,009

One striking trend, exemplified magnificently last year, has been an enormous increase in *bequests* to Final Exit Network. Much of this money came from benefactors who had not even used FEN services; they simply believed in the work done by FEN and wanted to make sure our compassionate presence would be available for future sufferers.

Bequests:

FY 2013-2014.....	\$ 3,395
FY 2014-2015.....	43,471
FY 2015-2016.....	80,513
FY 2016-2017.....	981,579



state you live in (coordinators are assigned by region) and you will receive a call from a coordinator who will explain the process of application and the criteria for acceptance.

How do I sign up for exit guide services?

Call us at 866-654-9156; tell the answering service that you want a guide. You will be channeled to the appropriate person, who will likely contact you within 1-2 days.

How do I volunteer to work with FEN?

Notify us by email or snail mail about your skills and experience, and where you suspect you could be especially helpful. We continually have these two needs: renewal callers and letter writers. Callers notify members when their membership renewal is past due. (Callers often find that

the lapse is due to forgetting or procrastination, and most members re-sign.) Contact treasurer FEN treasurer, Judy Snyderman for information.

Letter writers respond to articles, editorials, or other letters in the nationwide media, mostly the press. Timeliness is an important factor in our written reactions. Contact Julia Hanway, who handles this project and will share some hints and some caveats.

What information do I need to put Final Exit Network in my will?

1. Our tax ID#: 80-0119137.
2. Our mailing address:
P.O. Box 10071, Tallahassee, FL 32302

Can I donate stock?

Yes. Follow same procedure as directly above.

Accessing Your Living Will

Nearly everyone reading this newsletter probably knows that living wills are a means of obtaining end-of-life wishes. And most of them realize that a living will is not a guarantee that those wishes will be seen or followed.

Final Exit Network makes compliance more likely through its partnership with U. S. Living Will Registry. But recently, a FEN Board member took his wife to a hospital and, even though she has a living will stored with the Registry and even though it was a prominent hospital, there was a lack of awareness of accessing the instructions. Should you run into a similar situation, it is hoped that this article will help.

The U.S. Living Will Registry is a secure, on-line database where you can store your advance directive and/or organ donor information. The document can be easily accessed by you, or any healthcare provider. It is completely confidential, just like a medical record. Once registered, you will receive labels to affix to your insurance card and driver's license stating your advance directive is registered. There is normally a charge for this service but, as a result of the organizations' partnership, it is free to FEN members.

Once you have prepared your living will and are ready to register it, contact FEN for the USLWR registration form by email (finalexitnetworkcontact@gmail.com). Complete the brief form and send it with your advance directive and/or organ donor information to:

USLWR
PO Box 2789
Westfield, NJ 07091

(Please do NOT mail it to the Network's mailing address. This will delay your registration.)

Healthcare providers will probably know how to access the Registry when documents are desired but, if not, you can pass along the following instructions: Visit the Registry website, www.uslwr.com, and click on the option to "Access Documents Using Wallet Card ID." The provider will be asked to enter the source (i.e., Final Exit Network) and the Regis-

trant ID# shown on the card. After logging into the registrant's file, the healthcare provider can view and print a copy of the registrant's advance directive.

Should you wish to access your documents—perhaps to view, alter, or add to them—go to the same site and click on "Personal Account Login." You will be asked to enter your username and password, which were established when you registered. After logging in to your account, you will be able to edit your material and print wallet ID cards.

If providers or registrants are unable to access documents via the USLWR website, they can call Registry Specialists and request a faxed copy of the advance directives. The toll free number to request a fax is 800-548-9455. ■

OLDEN TIMES



OPTIONS *continued from page 6*

in this case, the client was lucky to have such family in agreement and willing to make sure final wishes were honored."

Meantime, about all you can do is ask questions. (Does your facility have a position on PAD? Do you have affiliates in California or Washington and, if so, what is their policy on PAD? Can you guarantee you'll honor my living will? What assurance do I have that your staff won't prolong my suffering at end of life? Do you condone a patient's VSED?) You may not get reliable answers from a marketing person trying to fill a vacant room and you can't trust that today's answer will still apply years in the future when needed, but questioning will give you an idea of the facility's mindset and, if nothing else, will let officials know that death with dignity is an issue. The trend seems to be toward heeding health documents, which bodes well for our wishes. ■

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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

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

YOUR MEMBER BENEFIT:

U. S. Living Will Registration

Have you registered your living will?

It is a benefit available at no charge to FEN members.

Call the Final Exit Network number 866-654-9156.

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

Our Guiding Principle

Mentally competent adults have a basic human right to end their lives when they suffer from a fatal or irreversible illness or intractable pain, when their quality of life is personally unacceptable, and the future holds only hopelessness and misery. Such a right shall be an individual choice, including the timing and companion, free of any restrictions by the law, clergy, medical profession, even friends and relatives no matter how well-intentioned. We do not encourage anyone to end their life, do not provide the means to do so, and do not actively assist in a person's death. We do, however, support them when medical circumstances warrant their decision.

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QUESTIONS?

Toll-free: (866) 654-9156

Please consider adding Final Exit Network to your will.

The only information you need is our
Tax ID number, 80-0119137, and our address:
Final Exit Network, PO Box 10071, Tallahassee 32302