

7 Stages of Alzheimer's



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Hospitalists Redux

By Richard Cleverly

We have much to share with you, I, Richard Cleverly, (R.) and my life partner, Diane Harris, (D.) in response to a rosy article that appeared some time ago in the newsletter about hospitalists. Readers will see our story in serial form: First, my own experience as patient, second, Diane's, as patient; in a subsequent issue, and finally, information about the H. system that helps lend clarity to the problems it engenders.

In the last two years, D. and I have been under the care of three separate hospitalists (H) in three different hospitals. Our trauma lingers, and our story needs telling, FYI.

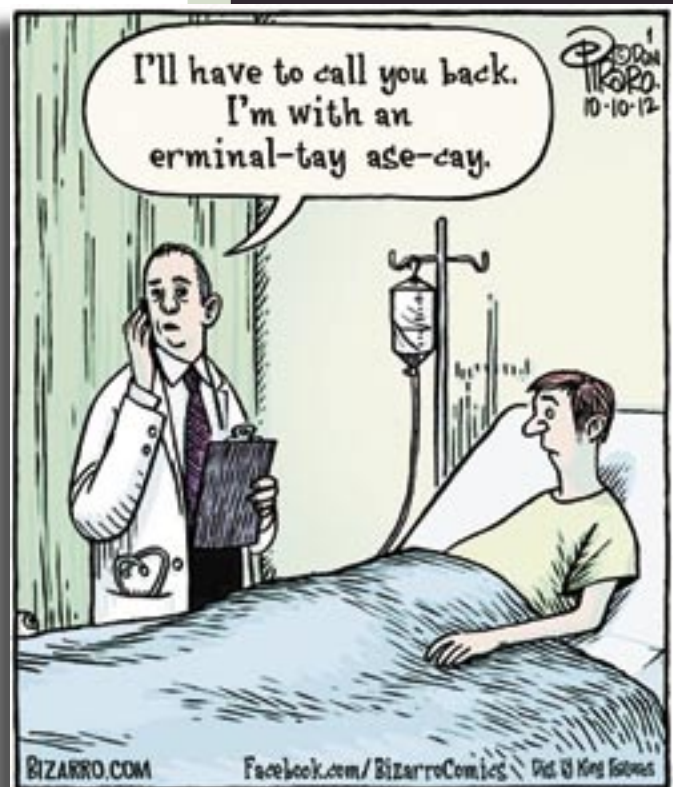
My Story:

I had had an emergency hospitalization for multiple, bilateral pulmonary emboli—an extremely painful and oft-fatal complication—a week after major foot and ankle surgery. I spent a long afternoon in unrelieved agony in the ER, waiting for H. to admit me. Morphine had been scripted, but the ER was a zoo, with no one available to administer it. When H. finally appeared, I was in fetal position, sobbing and begging for relief from the pain. H. told us, in obvious indifference, “You

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Dalton Baker

*Final Exit Network has lost
one of its most valuable soldiers.*

Dalton was born in St. Louis, MO. He served in the U.S. Air Force as an aerospace engineer there and at McDonnell-Douglas. When he retired from the aerospace industry, he devoted himself to hospice, mentoring school children, and volunteering in community theater. He was a stalwart of his city's Ethical Society. Passionate about fitness, he took lengthy cycling tours and played senior softball.

Dalton Baker entered the death-with-dignity movement by forming a Hemlock Society chapter in his hometown and served as a Caring Friend for Hemlock's national program. When that was disbanded, Dalton switched to the Network's similar program, compassionately supporting those near the end of life by providing information and his presence, if requested, at the time of dying.

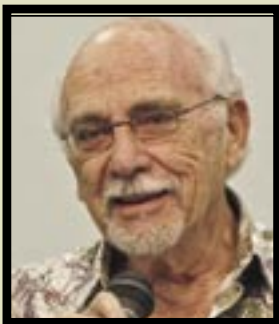
When Dalton's and his brother's homes were raided by the GBI in 2009, doors were broken down, computers and records confiscated- all later to be returned with an apology from the court. Dalton was treasurer of the Network then, and the experience shook him.



FEN's moneys were also taken- later returned by a court order.

In the early years of Final Exit Network, Dalton was both planner and leader of training sessions for its exit guide applicants. He was himself a senior exit guide and first responder.

Dalton was married twice and is survived by his three sons.



The man deserved a peaceful dying process after working so hard to achieve one for everyone else, and the fact that he died alone distresses me greatly.

Dick MacDonald, M.D.

I inherited the position of treasurer from Dalton, and he had made it so easy. He extended the utmost patience to me, explaining everything and answering endless questions. I also considered him a friend. I will miss him.

Judy Snyderman





Derek Humphry

This news brings deep sadness to many of us who have known Dalton through his strong commitment to Hemlock, and then to FEN.

Working with him in cases was always a privilege; he was a role model for both compassion and objectivity. He took such responsibility in handling any task that he took on: as FEN treasurer, handling with rare professionalism and competence the trauma of having both his and his brother's homes battered by the Georgia Bureau of Investigation. When GBI absconded illegally with FEN's funds, he acted quickly to protect as much as possible and succeeded in stanching the bleeding. His contributions to the training of new guides were always performed with valuable input and great respect for the applicants. And he contributed endless hours in the process of polishing and tweaking our by-laws.

Faye Girsh

Forgive my bursting my buttons, but one of my life's great accomplishments was bringing Dalton Baker into the Final Exit Network tent. Actually, he came in of his own accord; I just opened the door. (People deserve kudos on their own for being strongly self-motivated!)

Years ago I had spoken in St. Louis in behalf of Hemlock, and Dalton approached me afterwards with much interest. He was inspired to start a group there and had me as a presenter several times at his Ethical Culture congregation as well as in a local synagogue. He became a Caring Friend and later easily segued into FEN.

The GBI raids zapped him, as his home and his brother's were brutally broken into and his computer confiscated. His confidence and trusting innocence were shaken: How can this happen here? In the U.S.? Of course, the legal outcome was gratifying to the defendants and to us other members, but those who endured it personally will likely never forget.

There was more. Dalton's brother, after progressing from "normal" through the relentless downward continuum of dementia, died of complications of Alzheimer's, leaving Dalton bereft.

When my son and his family lived in St. Louis, it was always a delight to meet with Dalton, take a walk in the park, or go to the City Museum with my grandson.

His passion for biking may even have exceeded his determination to help people achieve a peaceful death!

We were so privileged and fortunate to have had him working with us in our ranks. His contribution was immeasurable.



PLATINUM SPONSOR

Thank You

Thank you to **Dan Carrigan**, of Peaceful Self-Deliverance, for the generous contribution of \$5000 for the World Federation Conference 2014.

We'd also like to thank our Illinois volunteers who committed themselves to this most successful conference: Deborah Scott, Joan Sophie, Edward and Elva Schneidman and Rick Konter.

need to follow the process.” After I was finally admitted, bringing the pain under control consumed most of that evening and lots of IV Dilaudid.

The next day, we were thwarted again by H.: The hospital pharmacy lacked four of my critical daily meds. Diane needed permission from H to bring my meds from home, to be dispensed by the pharmacy.

D. called H frequently for an OK; calls were not returned. So she just brought them. Three hours later, H. approved the meds during a hasty, pop-in visit.

A hospital discharge would require proper test results of my Coumadin blood level, which were too low. Nevertheless, H. kept haranguing me about Medicare’s length-of-stay regulations, that the hospital couldn’t keep me much longer. On the third day, after an OK test result, H. moved immediately for my discharge, despite profound

weakness and co-morbid conditions. D. called my primary care physician, urgently asking for help. My doctor explained that since I was officially under the care of H., the discharge was not in her power. “Fight it!” she said.

I was able to effect a one-day postponement. H. left the room, smirking: “I hope Medicare will approve this!”—an important statement delivered with neither explanation nor empathy.

* * * * *

On a vacation out of town, I became gravely ill with shigellosis, a bacterial infection particularly serious in the elderly. The ER doc recommended admission; my temperature was 105. A 5-hour wait preceded my admission orders by my new H., with 7 hours elapsing before I was finally transferred to a bed.

H. discontinued all my meds “in order to allow a proper diagnosis,” even though the abrupt interruption of several of those meds was known to be capable of serious repercussions. Predictably, severe side effects resulted from their absence, rendering my already “very grave” condition even worse. Se-

verely ill—intermittently delirious and confused—I had only D. to assert my patient rights. However, on Day #2, Diane herself awoke with severe intestinal pain and spent seven hours in the ER. Immediately after same-day discharge, she rushed to my room, finding me in extreme distress.

She demanded that the nurse immediately contact H, who ordered only 3 of the withheld meds to be dispensed within the next hour. One vital medication was not offered until late that evening, when I began convulsing so badly that my IVs came loose and set off alarms. I had begged in advance for this medica-

H. responded, smugly, “You can dispute the discharge but I want to warn you that I always win. Medicare always sides with me.”

tion, warning the dismissive H. about convulsions. A very responsible nurse managed to obtain the proper med, administer it, and stay until it started to work

Still, the hospitalist would neither return D’s repeated calls nor give permission to bring the rest of my meds into the hospital. The nurses informed her, “He only makes one call; if you’re not there he won’t call back. He’s already called you once.” Diane asked for H. to be paged, but he “wanted no pages from relatives.”

We thought of contacting a specialist but were advised that only H. could make that request. We considered firing H, but it was necessarily to inform H. directly. I was too ill to do so, and H. would not return D’s calls. Several times we requested a hospital social worker or someone with authority. We were told, “We put in a request.” But no such person contacted us.

On the third day, D. was finally successful in getting H. to approve bringing the absent drugs from her hotel room.

At that point there still was no diagnosis. I was being treated shotgun-style for both viral and bacterial infections. Nonetheless, prior to receiving the results of a crucial diagnostic stool culture, H. opined that it was probably viral and therefore untreatable, while facilitating my discharge. Because of the severity



Richard Cleverly

of my illness and destabilization from not receiving proper meds, I was very weak and still in diapers. That afternoon the stool culture confirmed the diagnosis of the shigellosis infection that had nearly cost my life.

After zero communication with me, H showed up bright and bushy-tailed on the next morning to start discharge procedures. I insisted on a phone call to notify Diane, whose protests of my weakened condition fell on deaf ears. She asked about an appeal to Medicare. H. responded, smugly, "You can dispute the discharge but I want to warn you that I always win. Medicare always sides with me." Aghast, D. stated, "So you're advocating for Medicare, against your patient?" "Yes," H said, and continued with the discharge paperwork, claiming the hospital could not keep me longer because "All your tests are normal." They were not.

A sudden phone call revealed that lab tests had "just come back," showing low magnesium levels. An IV infusion was required before they could discharge me. Four hours later, properly infused, I left, spending the next three nights in a hotel, gathering enough strength to fly home.

At home, we discovered a last straw: a message on our answering machine from H., who had called our home number instead of the hotel and cell numbers Diane had so meticulously left. ■

UPDATE: HEARING IN MINNESOTA

Trial of Exit Guides in Minnesota Set for May, 2015

The trial of Final Exit Network and two of its Exit Guides on charges brought in a rural Minnesota town has been scheduled to take place beginning on May 4, 2015.

Dakota County District Judge Christian Wilton conducted a hearing on December 8 in Hastings, southeast of the Minneapolis-St. Paul area, discussed the attorneys' scheduling issues, and picked the date for the month-long trial to begin. He and the attorneys also set aside February 26-27 for hearings on all pretrial motions. One of the major issues will be how to instruct the jury on the meaning of "assisting" in a "suicide."

Judge Wilton was recently assigned to replace Karen Asphaug, who had previously presided but recused herself for undisclosed reasons in September. "This was our first opportunity to visit in person with Judge Wilton, and all the attorneys on the defense team



*FEN General Counsel
Robert Rivas*

were favorably impressed with his demeanor, his knowledge of the case, and his diligence," said the Network's general counsel, Robert Rivas.

The Network and four of its volunteers were indicted in May 2012 on charges stemming from the 2007 death of Doreen Dunn, 57, in Apple Valley. One of the defendants has died, and all charges have been dismissed against another.

The trial was postponed for more than two years while the Network battled successfully in Minnesota's appellate courts to narrow the scope of the charges. Where the Network and its Exit Guides were charged with "advising," "encouraging," or "assisting" in a "suicide," giving the State three different potential ways to obtain a conviction, the Network's appeals have established that the State may try the defendants only on proof that they actually "assisted" in the "suicide," a felony.

The defendants are also charged with interfering "with the body or scene of death with intent to mislead the coroner or conceal evidence," a misdemeanor. ■



AARP is doing it again!

AARP has refused to rent us an exhibit space at their convention in May in Miami.

Well, we're doing it again, too. We're going to publicly protest their head-in-the-

sand attitude and their refusal to tell their members about choices in dying. Volunteers are needed for our protest. Unfortunately, we cannot pay travel or lodging, so if you live nearby, we especially need your help.

If you could possibly help for a few hours, contact:

Marty Seidenfeld: Phone: (208) 272-0292

Email: martyseidenfeld@gmail.com

Come on down and let's have some fun in the sun.

Above, from left, Marty Seidenfeld and Faye Girsh joined other FEN members during the protest at the San Diego AARP Convention.



For the LOVE of Mike

By Jerry Metz, M.D.

If I didn't keep going I was afraid I'd balk. Sheer momentum might work. One foot in front of the other, and keep moving. He was getting worse; that much was clear. Friends had said, "Try another doctor." I had considered going with Mike on our favorite hike as a last farewell. "Procrastination!" I saw that clearly now. The time had finally come: we walked down the dirt road to a meadow behind the barn, and I distracted his attention and put a bullet through his head.

We had been friends a long time, ever since that love-at-first-sight moment when I saw him jumping up and down, fenced away from the others because the pound could hardly handle his enthusiasm. Or size. "That's a man's dog," I said to myself, and I brought him home.

Big Mike was a hundred pounds of happiness, a Yellow Lab more handsome than bright, whose scythe-like tail swept cups and glasses off the coffee table in blithe oblivion, and whose warm body and wish to snuggle took the edge off many a frigid Maine night. If we hiked near water he invariably came home dripping. Playing "fetch" with just one ball was hopeless because he would return and stand expectantly, being wagged by his tail, awaiting my throw but not realizing I couldn't toss the ball he was still drooling over. "He's a shingle short," the locals said, but everyone loved him and he returned the favor.

Summers swept past and his muzzle turned white; his hind legs stiffened but his enthusiasm remained unchanged. With the awkward gait came the shameful poops on the rug. I didn't disapprove because I knew it was involuntary, just as he clearly knew it was wrong. From poop to pee in a few months, prescriptions be damned. Banish him to the barn to spare his life? What life is that? It would have broken his big heart. And mine.

There was only one way out. A maxim from a half-forgotten novel stuck in my memory: a man shoots his own dog. That final act of love can't be delegated, and it has to be done right and part of doing it right is not postponing, not making excuses, not dwelling in denial.

One crisp clear December morning Big Mike trudged with me and the other dogs down a quarter mile of driveway to get the Bangor Daily News. I had my coffee and was trying to concentrate on the editorial page when the news came to me: the time had come. No more delay. Now, or perhaps never. I slipped a can of dog food into one jacket pocket, a pistol in the other, and called, "C'mon, Mike!" The tail got lively.

When we arrived at the meadow I snapped open the can and poured a pile of chicken and gravy on the cold ground. The wagging accelerated. His head moved into one predictable location as I snapped the safety off and pulled the trigger. I was paying such close attention I hardly heard the noise. Must kill instantly! Must aim right! He must never know what hit him!

He fell onto his side, and the tail—that tail!—kept wagging! Impossible!

I fired again. Again! My glasses were spattered. Blood gushed but the tail still wagged!

I looked to the clear sky and screamed a ragged primitive cry, fell to my knees and wailed, shoulders shaking. Mike was gone. My Big Mike was gone! My big ol' big ol' big ol' Yellow Lab.... God! Mike!

I often visit his grave, remembering the good times, trying to take in the message he brought and trying to repress the intruding image of his bloody end and the tail that wouldn't lie down. At times I attribute the motion of his tail to "nerves," to a convulsive action resulting from brain circuits gone haywire, but occasionally I believe he knew the depth of my love and was telling me I had done the right thing.



Barbara Mancini's New Career: DWD Advocate

Barbara Mancini, the Philadelphia nurse prosecuted for handing her 93-year-old dying father his prescription morphine, has quit her job and is devoting herself to advocating for state death-with-dignity laws. Mancini, 58, has been traveling the country, telling audiences that she was wrongly prosecuted, that her father's end-of-life wishes were clearly stated and cruelly ignored, and that the hospice involved failed him.

She is haunted by what happened to her father and to her. "I'm trying in my mind to make this right for my dad. I'm doing it for him," Mancini said after speaking to 70 senior citizens at a Free Library of Philadelphia branch. "And I want to warn people that criminal statutes like PA's against assisted suicide are being misused, that what happened to me could happen to them."

Mancini said she treasured a handwritten note from Brittany Maynard, a new icon in the death-with-dignity movement, which she received the day before Maynard ended her life on Nov. 1, 2014.

Maynard, 29, a California newlywed who suffered from brain cancer, had moved from California to Oregon, one of five states where doctors can legally prescribe a lethal dose of drugs to a dying person, so that she could choose her time, place, and manner of death. A video explaining her decision has gone viral.

Mancini had written to Maynard praising the young woman's selflessness and courage, and sharing her own reasons for becoming an advocate.

MANCINI continued on page 8

BEQUESTS, LEGACIES & DONATIONS

There's a change in the air. Have you noticed? Wherever you look, there are tidbits and snippets of an awareness of end-of-life issues that have heretofore been invisible. There are editorials in unexpected newspapers, books and movies everywhere, emerging out of the fog of ignorance and denial and insisting on our attention. Interviews have been on the radio and TV, some involving our most knowledgeable and eloquent speakers, like Faye Girsh, Dick MacDonald, M.D., Derek Humphry, Frank Kavanaugh, familiar with the most minute details of our early history.

Some of our busiest affiliates have been scheduling regular meetings with speakers, ratcheting up the publicity, marketing their meetings with increasing finesse and confidence.

Our death-with-dignity movement is indeed on the move, and we, its advocates, are on the cusp of societal change. We know, having just hosted the World Federation of Right-to-Die Societies conference in Chicago this past September, that all over the globe there are people and organizations defying the status quo, changing laws, fighting for the right to determine when their misery is more than they can bear, and to opt out.

Most of our real work is done by volunteers, at every level. Your contributions do not pay for high salaries and fancy offices.

We need you to remember us in your wills, dear friends, so that through the generations, your progeny will know the peace at closing time that both you and we want for them, and the knowledge that we- through your generosity- can provide it. What a beautiful legacy that will be.

Talk with your estate planners, your financial advisors. Let them help you work out a plan that gives you an advantageous tax setup that will feel good come April 15th. And remember; we are a 401(c)3 registered non-profit; your gifts and donations are deductible to the full extent allowed by law. (Our tax-ID EIN number is 80-0119137.) ■



Judy Snyderman

“It comforted me to see your work and the power of your story,” Maynard wrote back. “Stories like



Brittany Maynard

yours and mine put human faces on a controversial topic that many politicians are happy to sweep under the rug. “I wish I could have had the pleasure of meeting you in person,” Maynard continued.

“This letter will have to do. I hope you continue to speak out on behalf of the terminally ill and our right to access dignity in death.”

Mancini was suspended from her job as an emergency room nurse at Lankenau Medical Center after she was charged with a felony count of attempting to aid a suicide, facing a potential 10 years in prison. Her father, Joseph Yourshaw, a World War II veteran, was enrolled in the Hospice of Central Pennsylvania and had indicated repeatedly—in a living will Do Not Resuscitate order and in hospice records—that he wanted to die at home and in peace. Yet when Mancini told a visiting hospice nurse that she had handed her father his morphine, the nurse called 911. Yourshaw was taken to the hospital and treated aggressively, but he died four days later.

Judge Jacqueline Russell dismissed the case after a year, concluding that state prosecutors had no evidence that Yourshaw had attempted to take his life, much less that Mancini had tried to help him. The judge said the case was “based on little independent investigation, significant hearsay ... speculation, guess. ...”

In her talks, Mancini recounts her story: “I stand here today as an example of what can happen when laws are taken to an extreme.” D.A. Kathleen Kane had prosecuted under assisted-suicide laws written decades ago with mentally unstable people in mind.

Oregon’s 1997 law states that a person who has been determined by two doctors to have six months or fewer to live and is mentally competent can request a lethal dose of medication. Dying people must ingest the drugs themselves.

A poll in late October found 40 percent of Americans—as many as 100 million people—had heard of Maynard and her cause, according to Barbara Coombs Lee, president of Compassion and Choices.

— Michael Vitez,
Philadelphia Inquirer, 2/15/14

SEVEN STAGES OF ALZHEIMER’S

[Note: We will likely all see ourselves in some of the stages and symptoms below. Our Medical Evaluation Committee members still thought the material important and timely enough to warrant inclusion.]

Text was taken from the website of the Alzheimer’s Association and is based on a system developed by Barry Reisberg, M.D., clinical director of the New York University School of Medicine’s Silberstein Aging and Dementia Research Center.

Alzheimer’s symptoms vary. The stages below provide a general idea of how abilities change during the course of the disease. Not everyone will experience the same symptoms or progress at the same rate. (Remember that it is difficult to place a person with Alzheimer’s in a specific stage as stages may overlap.)

STAGE 1: NO IMPAIRMENT

(normal function)

The person does not experience any memory problems. An interview with a medical professional does not show any evidence of symptoms of dementia.

STAGE 2: VERY MILD COGNITIVE DECLINE

(may be normal age-related changes or earliest signs of Alzheimer’s disease)



Your local Alzheimer’s Association chapter can connect you with the resources you need to cope with the symptoms and challenges of Alzheimer’s. helpline 24/7.

You’ll find Alz’s. “10 Signs” informative and probably comforting. (Will appear in next NL.) Alzheimer’s Association: 1-800-272-3900



The person may feel as if he or she is having memory lapses — forgetting familiar words or the location of everyday objects. But no symptoms of dementia can be detected during a medical examination or by friends, family or co-workers.

STAGE 3: MILD COGNITIVE DECLINE

(Early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms)

Friends, family or co-workers begin to notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration. Common stage 3 difficulties include:

- Noticeable problems coming up with the right word or name
- Having noticeably greater difficulty performing tasks in social or work settings. Forgetting material that one has just read
- Losing or misplacing a valuable object
- Increasing trouble with planning or organizing

STAGE 4: MODERATE COGNITIVE DECLINE (Mild or early-stage Alzheimer's disease)

At this point, a careful medical interview should be able to detect clear-cut symptoms in several areas:

- Forgetfulness of recent events
- Impaired ability to perform challenging mental arithmetic—for example, counting backward from 100 by 7s
- Greater difficulty performing complex tasks, such as planning dinner for guests, paying bills or managing finances
- Forgetfulness about one's own personal history
- Becoming moody or withdrawn, especially in socially or mentally challenging situations

STAGE 5: MODERATELY SEVERE COGNITIVE DECLINE (moderate or mid-stage Alzheimer's disease)

Gaps in memory and thinking are noticeable, and individuals begin to need help with day-to-day activities. At this stage, those with Alzheimer's may:

- Be unable to recall their own address or telephone number or the high school or college from which they graduated
- Become confused about where they are or what day it is
- Have trouble with less challenging mental arithmetic; such as counting backward from 40 by subtracting 4s or from 20 by 2s

- Need help choosing proper clothing for the season or the occasion
- Still remember significant details about themselves and their family
- Still require no assistance with eating or using the toilet

STAGE 6: SEVERE COGNITIVE DECLINE (Moderately severe or mid-stage Alzheimer's disease)

Memory continues to worsen, personality changes may take place and individuals need extensive help with daily activities. At this stage, individuals may:

- Lose awareness of recent experiences as well as of their surroundings
- Remember their own name but have difficulty with their personal history
- Distinguish familiar and unfamiliar faces but have trouble remembering the name of a spouse or caregiver
- Need help dressing properly and may, without supervision, make mistakes such as putting pajamas over daytime clothes or shoes on the wrong feet
- Experience major changes in sleep patterns like sleeping during the day and becoming restless at night
- Need help handling details of toileting (for example, flushing the toilet, wiping or disposing of tissue properly)
- Have increasingly frequent trouble controlling their bladder or bowels
- Experience major personality and behavioral changes, including suspiciousness and delusions (such as believing that their caregiver is an impostor) or compulsive, repetitive behavior like hand-wringing or tissue shredding
- Tend to wander or become lost

STAGE 7: VERY SEVERE COGNITIVE DECLINE (Severe or late-stage Alzheimer's disease)

In the final stage of this disease, individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases.

At this stage, individuals need help with much of their daily personal care, including eating or using the toilet. They may also lose the ability to smile, to sit without support and to hold their heads up. Reflexes become abnormal. Muscles grow rigid. Swallowing may be impaired. ■

Prophylactic Suicide

End-of-life care is receiving more and more attention in the media of late. The physician Ezekiel Emanuel, in a much-talked about essay in *The Atlantic*, announced that he will take no steps to extend his life once he reaches age 75, and he explicitly rejects assisted dying. Surgeon/writer Atul Gawande's latest book, *Being Mortal*, discusses how medicine needs to rethink its approach to aging and dying.

Perhaps the moment is right for broaching the idea of "prophylactic suicide": the decision of an elderly person to pre-empt the grim reaper and avoid the disabilities of extended life.

Death-with-dignity organizations such as Final Exit Network, Compassion & Choices, Death with Dignity, and others both nationally and globally are campaigning for dignified terminations of life for those with incurable diseases. They have had some success, since Oregon, Washington, Vermont and Montana have recently established the right to aid-in-dying.

Joyce Appleby proposes an excellent idea, but she is not the first. In 1998 a Canadian professor, C.Prado, wrote a book: *The Last Choice: Preemptive Suicide in Advanced Age*, available on Amazon, where this summary is published:

The *Last Choice* establishes that preemptive suicide in advanced age can be rational: that it can make good sense to evade age-related personal diminishment even at the cost of good time left. Criteria are provided to help determine whether soundly reasoned, cogently motivated, and prudently timed self-destruction can be in one's interests late in life. In our time suicide and assisted suicide are being increasingly tolerated as ways to escape unendurable mental or physical suffering, but it isn't widely accepted that suicide may be a rational choice before the onset of such suffering. This book's basic claim is that it can be rational to choose to die sooner as oneself than to survive as a lessened other: that judicious appropriation of one's own inevitable death can be an identity-affirming act and a fitting end to life.

Of course, there was Maude's decision to die at 80 in the movie *Harold and Maude*, and Australian/French woman, Lisette Nigot, to also die at 80 as seen in the documentary, *Mademoiselle and the Doctor*. (The doctor is Philip Nitschke). ■

— Faye Girsh

My proposal goes a step further, extending that right to people before they face terminal or debilitating illnesses.

With nearly half of people 85 or older suffering from Alzheimer's disease, concerns about quality of life in old age are reasonable, even if opinions about what to do about the situation vary widely. Currently, getting assistance to die is illegal, however sane prophylactic suicide might be.

Yet a recognized right to assisted suicide for those over 80 would ensure a painless death and allow an elderly person's loved ones to be there at the end. Now 85, I know I would appreciate having that choice and the peace of mind that accompanies it.

Making prophylactic dying legal would certainly prompt a much-needed discussion about what it means to prolong life without prolonging the capacity to enjoy it. ■

— Joyce Appleby, *New York Times*,
"Invitation to a Dialogue,"
11/12/14

EXIT GUIDE TRAINING: JUNE 17-19, 2015, CHICAGO

Exit guide services lie among those at the heart of Final Exit Network and are offered by trained, committed and compassionate volunteer members of FEN. If you see yourself in this description, you may want to apply for training as an exit guide.

This Chicago training is expected to be small, limited to applicants living in the eastern or midwestern states. We need people who are able and willing to travel, sometimes on short notice, those with flexibility to adapt to changing situations, detail-minded people, who have the willingness to put first the member being served, and who can communicate with empathy and kindness. It is crucial to have guides who will make a commitment to a case, once accepted.

If you are interested in applying to be an associate exit guide* and believe you can meet the above criteria, please contact Joan Sophie at jsophie@gmail.com, or at 773-944-0760 to receive an application. Applications must be submitted by 4/7/2015. ■

(* Highly experienced, veteran guides are "senior guides.")

[Note: This email was written in response to an interview on NPR's "Diane Rehm Show," in the Tucson area.]

GOOD GRIEF, DIANE!

When are you going to stop wasting time on your otherwise excellent program with power-mad physicians and others who would try to dictate our lives and deaths? I can't be alone in not wanting to hear their BS any longer!!

I'm so sorry that that mad doctor completely dismissed as "silly" what you went through with your dying husband, implying that your husband was a wuss because he didn't want to suffer a protracted dying. Kudos to you for standing up to him and his profound disrespect and insensitivity!

If you ever want to expose your huge and progressive audience to the only organization in America that has some real answers and information for anyone in a hopeless and suffering state, who want the choice to end their misery, I'd be glad to put you in touch with several other members of Final Exit Network.

Compassion & Choices, the group you feature, could not help me to hasten my death without my moving to one of only a handful of states with legal physician aid-in-dying.

I know I've been pesky and persistent, but listening to this nonsense is maddening. Just say the word, and I'll introduce you to some genuinely compassionate folks from Final Exit Network who will speak honestly with you about ALL the options available now to end our personal torture and place autonomy back in our own hands, where it belongs.

Renée Neuman

* * *

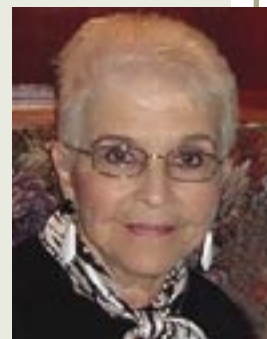
POTPOURRI

My recent guide in India raved about a 2010 movie, *Guzaarish*, beautifully made, about a popular quadriplegic radio show host who petitions the court in India for help to die. I bought a copy on Amazon, but it can also be screened on the internet. I was impressed that Bollywood

FYI continued on page 12

Cartoon Coordinator Needed

I often have members ask if there is any way they can help me do my job (and reduce my constant complaints about overwhelm, no doubt.) I rarely have any suggestion to make, since most of what I do requires me. However, there is a project which would be perfect for a volunteer, and it even carries a title: Cartoon Coordinator! You couldn't volunteer for anything that would be more fun, and you'd be performing a huge service.



Lee Vizer
Editor

The task involves 3 aspects. #1 is looking through cartoon libraries of various artists and selecting one a month for the NL, relative to the subject of death with dignity. (That's the hard part. The content is quite specific and sometimes hard to come by.) But while you're searching, you can have a lot of laughs. (That's the fun part!)

You need to be comfortable dealing with the Internet.

Part #2 involves communication either with the artist or his/her agent for a rental price. Sometimes, if the artist supports our cause, the royalty fee will be waived. I will aide you in both aspects of getting the process down pat, with info that will help.

Part #3: Arranging for treasurer Judy Snyderman to send the agent a check. That's easy.

It sounds more complicated than it is. Email me, and we'll "talk." There's no obligation. ■

— *Lee Vizer, Editor* lvizer@verizon.net

handled the subject so sensitively.

Two recent films, *The Theory of Everything* (about Steven Hawking) and *Life Itself* (about Roger Ebert), make a strong case for living despite severe physical handicaps.

In our bi-monthly Right-to-Die Film Festival, sponsored by the Hemlock Society of San Diego, we show relevant films at local libraries. *The last was One True Thing*, with Meryl Streep. Set in 1988, the painful situation of a woman with terminal cancer reflects a still-relevant, difficult family trauma. On February 22 we will experience the Italian film, *Honey*, about a young woman who helps people die.

A panel discussion by veterinarians on “*How to Die like a Dog*” was the topic for the 1/18/15 meeting. All sessions are free and public. (see www.hemlocksocietysandiego.org)

—Faye Girsh

* * *

An article appeared in the San Francisco Chronicle, 1/24/15: “*Merla Zellerbach: A struggle to have death-with-dignity*,” by Leah Garchick, where Ms. Garchick describes and reacts to the process as experienced with Compassion and Choices.

Richard Cone was inspired to respond in the following letter to the editor.

“Merla Zellerbach’s struggle to die with dignity accurately reflects the dilemmas faced by all of us who wish to do the same. In addition to the limited options described in the article (stopping eating and drinking, hoarding medications, terminal sedation), a quick and painless death is legally available by other means, such as inhalation of helium gas.

“The non-profit organization Final Exit Network provides detailed instructions about dignified means for ending life and also offers a personal presence at the bedside at the time of exit.

“While assisting a death is a crime, providing information and emotional support is not. It is regrettable that neither the health-care work-

ers nor Compassion and Choices volunteers informed Ms. Zellerbach about other options, such as Final Exit Network.”

— Submitted by Wendell Stephenson

* * *

Whatever happened to the historic concept of separation of church and state that our Founders slugged out a long time ago? Do we not realize that religious non-profits enjoy the same privileges that we taxpayers pay for, like paved streets and sidewalks and fire and police and sewer services, and that we foot the bill for their free services?

Now: Tell me a business for which the taxpayers pay money for the privilege of having the businesses not do what the customers need. We pay extra taxes to pay for what the non-profits do not pay, and then some refuse to perform the services, like end-of-life care that honors living wills, plus a whole slew of reproductive rights.

In Part 5 of the *Directives by Catholic Bishops for Hospitals, “Issues in Care for the Seriously Ill and Dying”*:

“Since a person has the right to prepare for ...death while fully conscious, he or she should not be deprived of consciousness without a compelling reason...Patients experiencing suffering that cannot be alleviated should be helped to appreciate the Christian understanding of redemptive suffering.”

We all pay for this “Christian understanding of redemptive suffering.” Because Catholic hospitals are tax exempt, everyone else’s taxes are higher. Plus, hospitals get federal funding, supplied of course, by the taxes we pay.

“So,” you vow, “I won’t patronize a Catholic hospital.” You may not have a choice. You may live in a small town where the only hospital is Catholic. Or, in this age of mergers, your own hospital may have merged with a Catholic hospital, and if the fancy machine you need is housed in the Catholic hospital, that’s where you go. Or you may be in the care, within your own hos-

I'm so glad you do the work you do.

I truly believe that in the next 25 years, most states—if not all—will pass a law that mirrors Oregon's leadership. I have written to my senators and the White House pursuing that end.

But I hope they will not copy the law in its present form: covering only those who have 6 months or less to live. The law should include sufferers with Alzheimer's disease, dementia, Parkinson's and other chronic illnesses which will eventually kill them. There are also extremely physically-disabled persons who strongly wish to end their misery without having to use a gun or other violent methods. Incapacitated persons, for whom there are no cures and who cannot speak for themselves, should be able to select guardians or other close proxies to make decisions for them, if they choose. Steps must be taken to insure that their decisions are voluntary and not coerced, nor the result of pressures from others. It's about choice and genuine self-determination in facing one's end.

Keep doing your work. Eventually the world will wake up and understand that, in the wake of intolerable suffering, gentle death can be a welcome friend.

— Jackie Alvarez

pital, of an attendant exercising her "conscience clause," exempting her from using a procedure that you need to keep you alive, because it "violates her conscience."

— Robin Goodwin,
with some source material from
Culture Wars, by Maria Alena Castle

* * *

"In Rio de Janeiro, police used to keep the number of murders in their precincts low simply by dumping the bodies in another precinct. That didn't prevent murders any more than banning self-deliverance prevents unwanted suicides. It just makes the books look better."

— Chris Docker, *Exit, Scotland*

* * *

Suicide ends all possibility of a worthwhile life. A deeply ill person who requests euthanasia doesn't have that possibility.

— Gustava Alphonso Quintana, *Colombia*

* * *

What does Final Exit Network offer most to people? Peace of mind. In contrast to suicide, we allow people to live more fully because of us, not to die too soon because of us.

— Fran Schindler, *FEN Coordinator*

* * *

Hospice was designed to promote end-of-life care, but because most patients apply too late, it has become brink-of-death care.

— Author unknown

* * *

YOUR LAST WISHES

NOTICE: Faye Girsh has compiled for ERGO an Advance Directive form (Living Will) which is similar to those you've seen or filled out, but hers is unique in important ways. The do's and don'ts promoting your wishes are there. But her pages verbalize the particular language and philosophies and the unique slant of us in the Movement. Girsh speaks our language and echoes our needs with subtlety, eloquence, and clarity. If you haven't checked your previous documents for a while, you may want to replace them with this remarkable version.

There is included a special section to be added to the traditional, that deals specifically with the possible onset of Alzheimer's Disease or dementia. Though it is not a "legal" document, it does carry the advantage of informing others what your wishes are, and who knows how invaluable that knowledge may prove?

To purchase: ERGO's Bookstore. Go to www.finalexit.org/ergo-store; select the sixth icon.

Digital Download pdf. is \$5. [Ed.]

* * *

Interested in more news on the right-to-die issue? ERGO circulates on a regular basis an electronic newlist with news from around the world. It is moderated by Derek Humphry. To subscribe (free) Click http://lists.opn.org/mailman/listinfo/right-to-die_lists.opn.org

— Derek Humphry

FYI continued on page 14

One Man's Opinion: A Senior Exit Guide Speaks

I can't tell you what it would be like to take my first and possibly my last breath of cool odorless oblivion. Zero calorie air. The act has everything to do with the person in bed and little or nothing to do with me. The patient's job is to follow the steps to transition, and my job is to stand by, to keep watch, to console, to reassure and to be prepared to speak whatever language they need to hear at that ever-so-critical time of life, its end.

You ask about resurrection, life after death, and I can speak that tongue even without believing in it. One doesn't have to be Puerto Rican to speak Spanish. Languages can be learned. Is my willingness to echo your idiom a con? A sham? Some kind of sick mocking joke? Not at all! My task is to be exactly what you need because this gathering is all about you and not about me. Whatever you can believe and express I can accept and reflect. The Roman playwright Terence said, "I am a man; I consider nothing that is human alien to me."

All my roommates in medical school were Jewish so I "speak Jewish" pretty well. Catholic? Most of the surgery I did was at a Catholic hospital and I revered the nuns for dedication made possible through the power of their faith. I understand. Unitarian? Well, that's easy. Agnostic? We humans should be proud of our ability to ask questions so enormous they cannot be answered. Atheist? Sure.

You've made mistakes? You're not the only one. We are told that Adam and Eve were commanded not to do the very thing that their inherent curiosity made inevitable, so Original Sin is a bum rap. Relax. To err is apparently divine.

You're afraid you'll go to hell for ending your life? My dear one, you're in hell right now and this is your chance to use your intelligence to escape! What did God do when his son cried out in pain and despair? Scripture says he ended the suffering and brought him home—the same

thing any loving parent would have done. How could we possibly be punished for following that example?

If you express fear I will ask you to go back, to count down to zero and try to remember what it was like to be you before you were born. What do you remember? Do you remember pain? Torment? Sorrow? You shake your head: you don't remember anything like that. I suggest that if there had been anything uncomfortable at that time surely—surely—you would have remembered it, and I would remind you of your present destination: back to where you were, back (for want of a better word) home.

A guide must provide a warm acceptance of each dying patient's philosophy, to sympathize and synchronize with that person's world view. While a Guide relates to the *unum* the Network deals with the *pluribus*, the broad spectrum of the public at large and so must maintain a keen and consistent neutrality in matters of philosophy and religion or risk being caught in destructive squabbles. It is only in this way that the Network can remain vigorous until this country becomes as enlightened as Oregon and we are out of work.

There is no escaping the cycle of life and death. Life is precious and death is useful. Our minds are big enough to love life but too small to fully understand it. Here is the secret that lets me play chameleon with honor, to share the language of a patient's heart and not to feel like I'm living a lie. We all pick up pieces of truth along the road and the pieces I choose might not match yours but the secret is this: the scraps are mostly metaphors, not literally true. Religious dogmas, codes of honor and the guideposts that comfort us are not incompatible once we see that they are merely symbols, road signs that point ... where? In a way I envy you: you're about to find out.

Farewell, friend. I'd love it if you could send a postcard. ■

— Jerry Metz, M.D

YES! *I want to support this important work.*

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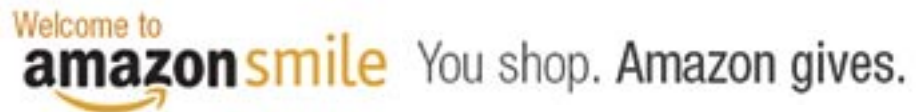
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Any questions? Please email erica@finalexitnetwork.org



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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Carter v. Canada

By Robert Rivas

General Counsel, Final Exit Network

The Supreme Court of Canada's February 6, 2015 decision in support of physician aid in dying is a masterpiece of legal prose that will have influence far beyond Canada's borders.

Patiently, methodically, rationally, and dispassionately, the 85-page opinion in *Carter v. Canada* sweeps aside one after another of the familiar arguments against physician aid in dying, or physician assisted death ("PAD").

While respectful of the opponents of PAD, it shows their reasoning consists of emotion, empty buzzwords, and factual claims that are not supported by the evidence.

The Supreme Court of the United States in 1997 considered setting a roughly similar precedent. At that time, there was no empirical evidence from any North American experiment to enable the justices to evaluate the validity of the opponents' fears. The Supreme Court of Canada decision shows that times have changed and evidence is available not only from foreign countries, but also from the Death-With-Dignity laws of Oregon and Washington.

Predictably, in *Washington v. Glucksberg*, the American justices unanimously rejected the claim that the constitution establishes a protected zone of personal autonomy in the relationship between a doctor and a patient who is competent, terminally ill, imminently dying, and suffering intolerably, a zone the government may not invade by making it a crime for the doctor to assist in the patient's death.

The *Washington v. Glucksberg* court held that the constitution does not support a constitutional right to PAD, neither did it require PAD to be illegal. The states were free to legalize it or criminalize it as they saw fit.

"Throughout the Nation, Americans are engaged in an earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide," the court held. "Our holding permits this debate to continue, as it should in a democratic society."

The United States Supreme Court often says the state governments "may perform their role as laboratories for experimentation to devise various solutions where the best solution is far from clear," and state-level experimentation may someday point the way to a national consensus. In *Washington v. Glucksberg*, Justice Souter said the states have "the power to experiment, moving forward and pulling back as facts emerge within their own jurisdictions."

He predicted "such experimentation" with the "emerging issue" of PAD would soon be attempted in some states.

The 1997 American decision shut down the constitutional argument for the indefinite future. But it planted a seed, and the seed may have sprouted in Canada.

Since *Washington v. Glucksberg*, the states of Oregon and Washington have provided ample objective proof that a well-regulated PAD program will not lead to the premature deaths of people who are merely in a temporary depression, those who are vulnerable, members of minority groups, the

disabled, or the impoverished. More recently, PAD has been legalized in Vermont, too, but no Vermont data were available yet in the Canada proceedings.

The Canadian trial court—whose decision was under review by the Supreme Court of Canada in *Carter v. Canada*—carefully analyzed the evidence from the Oregon and Washington experiments with PAD. Based in large part on the American experience, the Canadian Supreme Court held that a "properly administered regulatory regime" of PAD "is capable of protecting the vulnerable from abuse or error."

Sooner or later, the Supreme Court of the United States will revisit its decision in *Washington v. Glucksberg*. When it does, one can only hope, the Canadian decision in *Carter v. Canada* will be persuasive.

The essence of the Canada decision is summarized, as follows, in its first four paragraphs:

It is a crime in Canada to assist another person in ending her own life. As a result, people who are grievously and irremediably ill cannot seek a physician's assistance in dying and may be condemned to a life of severe and intolerable suffering. A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. The choice is cruel.

The question on this appeal is whether the criminal prohibition that puts a person to this choice violates her rights to life, liberty and security of the person and to equal treatment by and under the law, as guaranteed by the Canadian Charter of Rights and Freedoms. This is a question that asks us to balance competing values of great importance. On the one hand stands the autonomy and dignity of a competent adult who seeks death as a response to a grievous and irremediable medical condition. On the other stands the sanctity of life and the need to protect the vulnerable.

The trial judge found that the prohibition violates the rights of competent adults who are suffering intolerably as a result of a grievous and irremediable medical condition. She concluded that this infringement is not justified. We agree. The trial judge's findings were based on an exhaustive review of the extensive record before her. The evidence supports her conclusion that the violation of the right to life, liberty and security of the person guaranteed by the Canadian Charter of Rights and Freedoms is severe. It also supports her finding that a properly administered regulatory regime is capable of protecting the vulnerable from abuse or error.

We conclude that the prohibition on physician-assisted dying is void insofar as it deprives a competent adult of such assistance where (1) the person affected clearly consents to the termination of life; and (2) the person has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. ■

Save the Date!

JANIS LANDIS, VICE PRESIDENT, FINAL EXIT NETWORK



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Why does the concept of suicide cause such outrage? presented by Janis Landis

Why do many psychologists allege that 'rational suicide' is an oxymoron? The Final Exit Network is the only organization in the United States that advocates for the right of competent adults to determine that due to irremediable medical conditions, the quality of their life is insufficient. This paper looks at the legal landscape in several States that have waged war against FEN and the right to self-determination. It provides an update on current rules including the Canadian Supreme Court decision, and it examines why the right to individual autonomy in the way we exit life has become the next battleground in the evolution of basic human rights.

Presentations (more to come)

- "Respect Beyond the Grave" Presented by Margaret Downey
- "Secular Patients Graciously Accept Second Class Status" Presented by Joe Beck
- "Stay" and the Secular Argument Against Suicide" Presented by Jennifer Michael Hecht
- "Dying with Dignity: Lessons from Stoicism & Co." Presented by Massimo Pigliucci
- "Do people have the "right to die"? Presented by Ana Lita, Ph.D.
- "Body Not Soul: Encouraging Organ and Body Donation After Death" Presented by Jamila Bey
- "Keeping Clergy Away: Preventing Unwanted Religious Intrusion Through Advance Directives." Presented by Marcia Cohen, Carol Anne Johnson and Debra Smietanski
- "'A Different Kind of Immortality" Presented by Anne Klaeyen
- "Cancer as Existential Crisis: Coping styles of believers and nonbelievers -- and a role for secular humanist chaplaincy" Presented by Ralph Lewis, MD

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