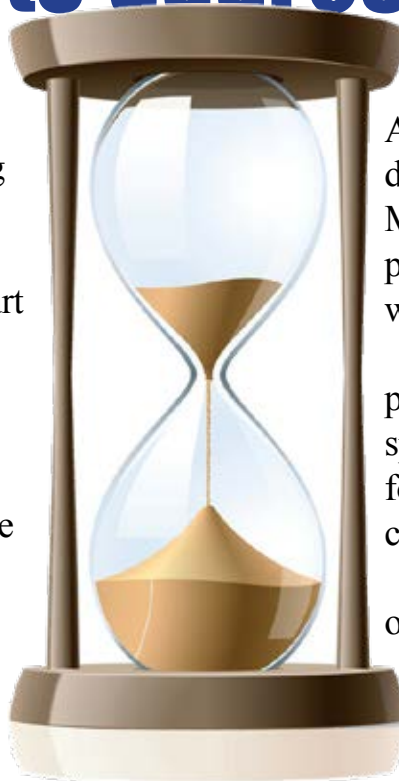


NOW is time to address dementia

Final Exit Network has created a new Advance Directive designed to prevent dying people from being force fed against their wishes – even if suffering from dementia.

What's more, FEN will go to court in an effort to set a legal precedent ensuring that VSED (Voluntarily Stopping Eating and Drinking) is always available to those who sign the Supplemental Advance Directive for Dementia Care.

This document, and the drive to make it legally binding, has been on our agenda for some time. We recognized the growing crisis



surrounding the explosion in Alzheimer's and other forms of dementia, because no state that offers Medical Aid in Dying accommodates patients who are not "of sound mind" when it is time to receive assistance.

Now there is a second, more pressing crisis: COVID-19. The specter of a ventilator is now reality for many of us who were already concerned about how we would die.

FEN is stepping up in this time of dual crises, and this edition of the magazine is keenly focused on what we all need to know.

– *Brian Ruder, FEN President*

Life (and death) in the time of COVID-19

By Lowrey Brown
FEN Client Services Director

The title is hardly original wordplay at this point in the pandemic, but it is a hat tip to Gabriel García Márquez, who, in his 1982 Nobel acceptance speech, began his description of utopia with, "where no one will be able to decide for others how they die."

He was speaking of oppression and the violence that robs so many of the right to shape their life stories, but I find it poignant that his

words apply equally well when applied to laws and social customs that would rob so many of the right to shape how their life stories end.

We at Final Exit Network are dedicated to our mission. Yet we recognize that there are missions greater than our own, and stopping the spread of COVID-19 is one of them. We are committed to protecting the health and welfare of our global community and supporting efforts to stop this pandemic.

COVID continued on page 2

Renew your membership online: www.finalexitnetwork.org

To that end, guides will not travel while there is a risk to themselves or others.

That does not mean we are idle – *quite the contrary*. As many of our readers know, the vast majority of people served by the Exit Guide Program never apply for guide support, let alone work with a guide. The needs of these callers are met by our coordinators, who are on the front lines answering questions, clarifying misconceptions, directing to resources, and discussing options.

They are still doing that, but with a coronaviral twist.

We have been getting a lot of inquiries related to COVID-19, which have been eye-opening in demonstrating how many people have not, in any practical way, thought through end-of-life scenarios or considered how they might prepare for different eventualities.

We have fielded multiple calls from worried individuals who want to know if we can help them if they get stuck on a ventilator with COVID?

Pause, and think about that question.

Even if it were legal to provide the equipment, which it isn't, and even if we were willing to flagrantly expose our guides to a highly contagious virus, which we aren't, how, exactly, do they think we would get into their room, deep in hospital quarantine, remove the ventilator, rouse them into consciousness from the sedation necessary for a ventilator, and guide them through an exit?

On the surface, the question might sound logistically absurd, but it isn't absurd if you have never considered the paths by which your life might end, or what you might be able to control in those scenarios.

We have been getting a lot of inquiries related to COVID-19 ... many people have not, in any practical way, thought through end-of-life scenarios or considered how they might prepare for different eventualities.

Fortunately, our coordinators are good at hearing the question behind the words, and they created a simple, one-page tool (inset) to help people express their priorities for medical care should they fall gravely ill from COVID or anything else during this time of resource shortage and aggressive triage.

If there is a silver lining in this tragedy, it might lie in prompting people to talk with loved ones about their health-care priorities and wishes for end-of-life

care. Coordinators are educating callers about advance directives and health-care representatives, about withdrawing medical care in a controlled manner, and about Voluntarily Stopping Eating and Drinking (VSED) to hasten their death.

Indeed, this situation has prompted us to expand our toolkit so we can better support individuals seeking the medical care they need to embark on VSED.

A planned self-deliverance is one path, but there are many others and – no matter how carefully one plans – life will dish up the unexpected, be it a sudden stroke, an accident, or a virus that lands you in the hospital on life support.

Do your loved ones know what you want?

Editor's note: The full-size document pictured above is available online by [clicking here](#), or by phoning Final Exit Network at 866-654-9156.



Dementia is not sheltered-in-place

By Janis Landis, FEN Board Member

As we age, we face limitations (Why did I just walk into this room?), and for the most part, we learn to live with them. We know that health issues are likely to multiply, and we will make decisions based on our personal beliefs: Fight to the last drop of strength – or decide to end the fight on our terms.

But dementia robs us of the ability to recognize our situation and the ability to carry out our end-of-life decisions. For most of us, this makes dementia one of the most feared – perhaps the single most feared – medical diagnoses.

To understand why dementia is so different in terms of personal choice requires a bit of explanation.

In all 50 states, it is settled law that competent adults have the right to refuse medical treatment. And crucially, since artificial hydration and nutrition

Dementia robs us of the ability to recognize our situation and the ability to carry out our end-of-life decisions.

(feeding tubes, etc.) are defined as medical treatment, you can include such prohibitions in your Advance Directive (AD). It will be honored even if you are no longer competent due to physical conditions.

For example, if you have excluded artificial feeding and lapse into a coma, your directive will be honored.

But a very important complication arises if you are deemed no longer competent due to dementia. All your medical directives will be honored. But your caretakers may offer you plates of food, and often try to tempt you, even if you are initially uninterested in eating.

In the view of many health-care providers, it is not considered “medical treatment” for them to offer food and liquids orally, and not through artificial means. Hand feeding is classified as ordinary care and comfort, like bathing and other bodily needs.

When you are no longer competent, you may react instinctively to the tempting plate of food and open your mouth. This reflex action is viewed by many state laws and judicial rulings as overriding your AD instruction to not be fed.

In other words, although you would now be

considered incompetent for any other legal purpose, you are considered competent to overrule your Advance Directive simply by opening your mouth. Caretakers cannot be prevented by your health-care surrogate from enticing you to do so.

To baby boomers used to great autonomy, this issue is a significant matter of increasing concern. Many organizations are trying to address it by suggesting specific additional instructions for ADs. However, by itself it is unlikely that a person’s amended directive is going to make any difference.

... we will provide legal counsel to assist your health-care surrogate in demanding that your care provider honor the dementia supplement to your AD.

Final Exit Network is the only right-to-die organization that has developed a plan of action designed to challenge these laws.

In the right circumstances, we will provide legal counsel to assist your health-care surrogate in demanding that your care provider honor the dementia supplement to your AD – our new document called the [Supplemental Advance Directive for Dementia Care](#) (SADD).

More importantly, we are prepared to litigate on your behalf to enforce compliance with your SADD – *at no cost to you or your estate.*

There is much more to be said about how individual cases will be selected and how this process will work (material for a subsequent article).

If this is an issue that concerns you, please read on and see FEN’s Plan of Action for Dementia, co-authored by Robert Rivas, our attorney who developed our Supplemental AD for Dementia Care.

FEN provides Exit Guide services to people who choose self-deliverance over a descent into dementia, when they would be no longer competent to choose their exit. Sadly, those people have “left time on the table” by having to act prematurely.

This special AD initiative is FEN’s bold step to make it unnecessary for anyone to sacrifice extra time they could have with loved ones.



FEN'S DEMENTIA PLAN OF ACTION

By Janis Landis, Board Member, and Robert Rivas, FEN Legal Counsel

FEN is launching a program to litigate for enforcement of an Advance Directive (AD) prohibition on hand feeding. The goal is to allow the individual with dementia to end their life through Voluntary Stopping of Eating and Drinking (VSED).

With appropriate palliative care, including pain medication, this can be a peaceful and dignified way to avoid the ravages of advanced dementia. Following are details about FEN's new program.

1. The Supplemental AD for Dementia

A copy of the [Supplemental Advance Directive for Dementia Care](#) (SADD) is on pages 6-7, along

Every FEN member will receive an email requesting volunteers for this program. We are looking for people who are experiencing the early stages of dementia ... but who are competent to execute an Advance Directive.

with advisory notes on its use. An official copy is available on our website to print and complete.

Before signing the SADD, the user must separately have a general purpose Advance Directive in place, along with an appointment of a health-care surrogate (aka, a proxy or a durable power of attorney for health care). Both documents should be kept together.

2. The current legal landscape

There is little legal guidance in state statutes and cases on whether a health-care provider is legally required to discontinue manual feeding and hydration based on an instruction patients included in their advance directives. In one of the few court cases, when a surrogate sought to initiate VSED for a severely demented patient, the judge refused to honor the surrogate's authority because the patient had not specifically included a VSED instruction in her Advance Directive.

The judge left open that he might support her choice of VSED if the AD was more clear. In FEN's *Supplemental Advance Directive for Dementia Care*,

Final Exit Network's plan is ... to shape the law of the future by establishing precedents today.

we seek to leave no ambiguity about the patient's choice.

3. The SADD program

Any individual who wishes to use the new supplemental AD on their own can do so. As mentioned, however, the ability to have it enforced is far from clear. To address this, we will be taking an additional, unique step, not available through any other right-to-die organization.

Every FEN member will receive an email requesting volunteers for this program. We are looking for people who are experiencing the early stages of dementia (diagnosed or not), but who are competent to execute an Advance Directive, or whose age and family history make them fear they will soon begin to experience dementia.

Volunteers will be asked to provide some basic information such as age, state of residence, contact information, and current health.

Robert Rivas, FEN legal counsel, will contact each individual to discuss the program and key criteria. For example, it is vital that the patient have a health-care surrogate who is supportive of the patient's request. There will likely be considerable pressure on the surrogate by care-givers to allow hand feeding.

In addition, the patient must be willing, if necessary, to be the subject of a civil action to enforce the SADD if its terms are not respected by a health-care provider. This could mean publicity.

Because court records are open to the public, the SADD user's name and that of the health-care surrogate could be published.

4. Objectives of this program

Final Exit Network's plan is to seek out opportunities to shape the law of the future by establishing precedents today. Virtually all health-care institutions

ACTION continued on next page



SADD not limited to brave litigants

‘You can’t force me to eat and drink.’

Final Exit Network’s *Supplemental Advance Directive for Dementia Care* (SADD) is available for you to use even if you do not wish to be a “test case” and participate in a litigation initiative. If you wish to complete the document on your own, a copy is available on our website.

But please remember that this directive is not for everybody. It’s only for savvy users of Advance Directives (AD), those who have given plenty of thought to this issue and have made up their minds: They would choose self-deliverance by VSED (Voluntarily Stopping Eating and Drinking) over being spoon fed interminably after they cannot or would not otherwise eat.

- You must also have a health-care surrogate who is completely comfortable with this request and who is prepared to argue with health-care providers on your behalf.
- You and your surrogate must also understand that there is very little legal guidance in state cases – *and that your request may not be honored*. However, inclusion of such a statement does help improve the chances of it being upheld, as well as generally contributing to a climate in which such requests become the norm.

On pages 6-7 is a copy of the supplemental AD for your information. Our website contains [an official copy you can download](#) and complete.

ACTION *continued from prior page*

treat hand feeding as a minimum standard of care that cannot be withdrawn.

Our goal is to make them treat it as a medical procedure – one that a patient has every right to refuse.

A patient would thus be empowered to choose VSED, which – when carried out with good palliative care, including pain medication – can be a peaceful and dignified way to avoid the pitiful and pointless final stages of dementia.

We will evaluate criteria and usefulness as we progress with this initiative. But be assured, there will never be any cost to participants, and if selected, you

may drop out at any time.

5. Next steps

1. If you wish to proceed on your own on this issue, use the SADD form [available on our website](#) and attach it to your current Advance Directive.

2. If you are interested in learning more about our program, and possibly deciding to participate, watch for our official email announcement that provides instructions on how to do so.



SUPPLEMENTAL ADVANCE DIRECTIVE FOR DEMENTIA CARE

This Supplemental Advance Directive is made by:

Name:

Address:

I make this Supplemental Advance Directive for Dementia Care to inform my health care providers, loved ones, and health care surrogate of my treatment instructions in the event I lack capacity to give instructions myself. I am fully competent at this time. I have a separate, general advance directive in place. I ask that my general advance directive be maintained in my patient chart and applied according to its terms and that it be supplemented by this Advance Directive for Dementia Care.

I have also completed a legal form to appoint a health care surrogate and trust my surrogate to demand that my general advance directive be enforced in circumstances where it applies and this Supplemental Advance Directive for Dementia Care be enforced in the circumstances where it applies.

This Supplemental Advance Directive for Dementia Care should be applied when my dementia has progressed to the point where, in the opinion of my health care surrogate, I do not recognize my family members, loved ones, and friends; where I cannot remember their names; or where I am not able to communicate well enough to make clear whether I recognize my friends and loved ones or remember their names. I will call this "My Chosen End Point." I would wish to die quickly and peacefully under those circumstances.

At My Chosen End Point, I wish to receive the best available palliative and hospice care and refuse any medical treatment that would serve only to postpone my death, including, for example, vaccines, antibiotics, or other antimicrobial drugs, antiarrhythmics, cardiopulmonary resuscitation, blood transfusions, or any artificial or mechanical means of life support. I do not wish to extend my life or prolong the dying process.

At My Chosen End Point, I wish to be allowed to die by VSED, or the voluntary stopping of eating and drinking. I do not want to be encouraged, persuaded, or forced to eat or drink. I do not want food or fluid to be held near my mouth to provoke me to open my mouth reflexively. I ask that the scent of food not be present in my room. I instruct that I not be hand fed or hydrated unless the lack of hand feeding and hydration appear to cause me physical or emotional distress

and I affirmatively appear to seek to be hand fed or hydrated to relieve the distress. Any palliative or sedative medication should not be given orally, if possible. Moistening of my lips to keep them comfortable should not be considered a form of prohibited hydration.

I insist that nothing I do be deemed a revocation of this Advance Directive unless I revoke it in writing at a time when I have the mental capacity to make and revoke an advance directive. In my view, hand feeding and hydration are forms of medical treatment and require the patient's consent. Today, while I am competent, I insist that I be allowed to die naturally by not eating or drinking at My Chosen End Point. Given that any other advance directive signed while I am competent is honored after I lack capacity, even if I would die as a result, there is no reason for my instructions regarding hand feeding and hydration to be treated differently.

I intend that my health care surrogate alone be the one to determine whether I have reached My Chosen End Point. I authorize my health care surrogate to take any legal action necessary to enforce my choice to die from VSED if I have reached My Chosen End Point.

I ask that any health care institution providing treatment for me maintain my advance directives in my chart and document prominently that these advance directives are in place, as required by 42 U.S.C. § 1395cc and any applicable state law. I ask that the health care institution's management review these documents and determine if the health care institution has any policy against the enforcement of their terms. If so, I ask that I be transferred to an appropriate health care institution that does not have such a policy.

Signed,

Dated on _____, 20____

We, the following witnesses, testify that we know the signer of this document and believe, based on our experience, the signer is competent to make the decisions reflected herein.

WITNESS NO. 1:

Address:

Signature

Name written legibly

SECOND WITNESS AND NOTARY FORM ON NEXT PAGES

COVID-19 raises questions about end-of-life equality

FROM EXECUTIVE DIRECTOR MARY EWERT



Lawmakers do for pandemic patients what they won't do for other dying people

First, I extend my warmest thanks to our FEN volunteers and staff who have done a magnificent job of supporting our programs during this challenging time.

COVID-19 ... pandemic ... shelter-in-place ... social distancing ... PPE ... these things were not on the horizon when I wrote the winter column. Now, staying safe amid a pandemic is the focus of our daily lives. This intrusion of death into our daily consciousness can be deeply disturbing, and yet it nudges us to ponder our end-of-life vision and take action to achieve the death we want.

Another frightening disease – dementia/Alzheimer's – is on the minds of many, especially aging baby boomers.

FEN recognizes the fear of those who face the prospect of slowly losing capacity and autonomy. That spurred FEN – with the able leadership of General Counsel Rob Rivas and President Emerita Janis Landis – to develop the Supplemental Advance Directive for Dementia Care (SADD) highlighted in this issue. I encourage you to read about the program, then consider whether you might want to participate.

Now, here's more relating to the coronavirus, which dominates news both here and abroad.

Pascal Landa of the French organization Le Choix – a member of the [World Federation of Right to Die Societies](#) – mentioned an article that appeared in the French newspaper *Liberation* on April 8. It was written by three physician members of Le Choix.

The article addresses a late-March decision by the French government to allow intravenous drugs that depress breathing to be sold to physicians in

pharmacies. Previously, this medication was available only to hospitalists.

The intent of this decree is to allow doctors to ease the suffering of COVID-19 patients dying outside the hospital, at home or in nursing homes.

From a compassionate point of view, it demonstrates that the government and medical profession recognize the need to help COVID-19

patients (with limited life expectancy) to die with minimum agony.

The article goes on to ask why, then, is it impossible to have legislation that recognizes

the need for all patients, in city and countryside, to have the option of a peaceful death outside the hospital environment?

The authors point out the discrepancy in the French government's response to COVID-19 patients versus those dying from other diseases at other times. Le Choix plans to bring the issue to the French Parliament once the pandemic crisis abates.

The COVID-19 pandemic will doubtless highlight similar global discrepancies in care. The suffering this virus causes highlights the fundamental ethical truth that we at Final Exit Network recognize: While life is precious, it is not infinite, and it's completely ethical for an individual (or their representative) to choose to end it if pain and suffering have become so acute that death is preferable to continued existence.

We at FEN will continue to advocate, both directly and through the example of our Exit Guide Program, for the recognition of this truth.

Last but not least, check out our new website at www.finalexitnetwork.org. We think you will like it, and we look forward to your comments.

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❧ VISION ❧

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

❧ MISSION ❧

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



"SEE, RIGHT HERE, RULE NUMBER 6...
'YOU CAN'T TAKE IT WITH YOU!'"

Bequeathed donations help keep FEN afloat

Almost 35 cents of every dollar in FEN's budget comes from a generous donation by someone who remembers us in his or her will.

Often, those contributions are from members or others who have been helped by our Exit Guide Program. (The service can be accessed by anyone who qualifies – being a member of Final Exit Network is not required.)

Their support for us, after we supported them, may be a way to say "thanks." More importantly, it is a way to "pay it forward" and ensure that others in similar situations can find a compassionate and dignified "exit" when it's time.

Please, *remember us in your will or name FEN as a beneficiary in your IRA or other financial product.* It's easy to do and does not require a lawyer. All you need is our tax ID (80-0119137) and address:

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His grass is looking greener

Lamar Hankins can finally cut it

By Jay Niver, FEN Editor

FEN members know Lamar Hankins as the cerebral writer, philosopher, and erudite moderator of [The Good Death Society Blog](#).

He's giving up that role because he wants more time to mow the lawn. Seriously.

"I never thought I'd be happy to cut my own grass at 75 and do the vegetable garden," he confessed. "It's taken me basically five years to get back to where I can do almost everything I used to do."

Ironically, Hankins's medical maladies were FEN's good fortune. His back, knee, hip, and other problems forced a more sedentary lifestyle upon him, which was not wholly terrible for a prolific writer who added blogging to his portfolio in 2017.

That summer is when he and FEN's Gary Wederspahn conspired to follow up on Gary's idea of a FEN-sponsored blog: a public forum for discussion of myriad right-to-die issues and "anything deemed relevant to end-of-life concerns." The blog now has more than 20 categories of entries, from mental illness to freedom of speech and ALS to organ donation.

That wasn't Lamar's only contribution to Final Exit Network. Since 2014, he has helped newsletter editor Lee Vizer as a proofreader, served as an Associate Exit Guide and Coordinator.

"In the midst of five major surgeries, I knew I didn't want to travel back then," he recalled. Coordinating, writing, and editing was work that wouldn't tax his surgically repaired joints and back.

To be fair, Hankins isn't giddy solely over lawn and garden tasks. He also looks forward to writing more about social and political topics, which he used to do.

Hankins will keep moderating the blog through July as it gradually transitions to Kevin Bradley's stewardship. No word on whether Bradley will bring the same liberal social consciousness that's ingrained in his predecessor.

'... the need for compassion is the greatest lesson I have learned in 75 years.'

"His anti-war views formed early in his life and (will last) until his death." We know this because Lamar penned it in his own obituary (to be edited by his wife June), which he shared for this story.

If it's wise to make an Advance Directive, it makes sense to be sure your obit says what you want.

Hankins practiced law for 40 years, but he wasn't

handling cases like Matlock or Mason. "I represented a lot of people for nothing," he said. "Almost never did I have a wealthy client."

Some seminal experiences shaped his views on social justice: "I spent one summer working in prisons and a year with VISTA and migrant farm workers," he said. "I learned how absolutely corrosive our prison system is to human beings, and the horrific abuse endured by people who pick our food."

On a lighter side, this "doting grandfather" wrote a series of short stories about his childhood for his granddaughter and enjoyed a life-long affair with classic folk music.

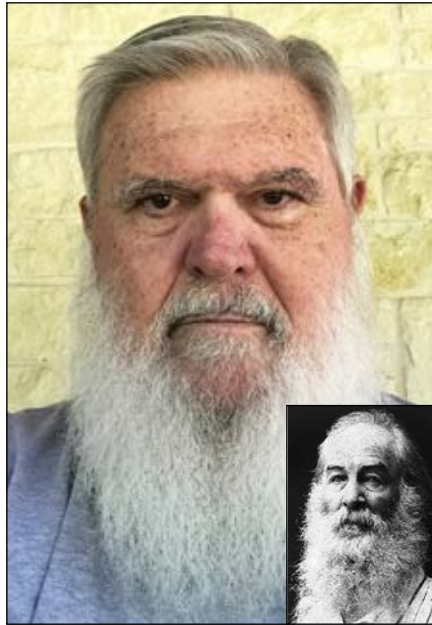
Lamar sometimes describes

himself as "a progressive populist," but he was a Democrat until Bill Clinton's "many social and political sins" drove him from the party. In hindsight, how bad was Clinton compared to today's White House?

Hankins responded with trademark candor and added, "No president in my lifetime has ever been so inept at governing as the present White House occupant."

His decades of community service speak louder than his authoritative voice. But when quizzed about his proudest achievement, he eschewed the question.

"I resist the notion of 'pride' ... If I have to say anything about my life, the need for compassion is the greatest lesson I have learned in 75 years."



ALL SMILES – Lamar Hankins took a selfie to capture his "Walt Whitman expression."



Times publishes letter by FEN President Ruder

The New York Times

Making Choices About Death



Chloe Cushman

April 2, 2020

To the Editor:

["I Love the World, but I Cannot Stay,"](#) by Mary Pipher (Sunday Review, March 8), captures a sentiment that many of us older people try to articulate to our families and friends. How do I want to deal with death and what should I expect when I die?

It makes me wonder why more people don't want to make efforts to manage their death in a way that supports their beliefs. I suspect that some people will be discussing this as they deal with the Covid-19 virus and all of its unknowns.

I, for one, want to live as long as I can without severe suffering or a significant loss of autonomy. I don't want doctors to tell me when I should die, and I don't want to waste a lot of money trying to live for a few more months.

I have procured the things I need for a peaceful death, and hope that I never have to use them, but feel very good knowing that I have them.

Brian Ruder
Portland, Ore.

The writer is president of the Final Exit Network.

[CLICK HERE](#) to see the article
("I Love the World, but I Cannot Stay") to which Ruder referred.

Oregon law keeps working as planned

America's first right-to-die law, passed in 1995 and implemented in 1998, continues to operate almost precisely as it was designed.

The Oregon Health Authority released in March the annual report for the 22nd year of the Oregon Death with Dignity Act, the world's first Medical Aid in Dying (MAiD) statute.

In 2019, 112 Oregon physicians wrote 290 prescriptions to dying Oregonians who qualified under the law, and 188 people died using the medications.

Similar to previous years, most patients: were 65 or older (75%), with the median age of 74; had cancer (68%); were on hospice at the time of death (90%); died at home (90%); had some form of health insurance (99%).

Consistent with past reports, the most frequently reported end-of-life concerns were loss of autonomy (87%), decreasing ability to participate in activities that made life enjoyable (90%), and loss of dignity (72%).

Since the first Oregonian used MAiD in 1998, 2,518 people have received prescriptions under the law, of whom 1,657 (66%) died from taking the meds.

These figures continue to underscore not only that just a small number of people use the law, but also that more than one third of those who receive the medication do not take it. They find comfort in merely knowing it is available to them.

While proponents cite Oregon's 22 successful years, MAiD has now logged almost 60 years' total experience nationwide without abuse.



A 'pet' peeve

By Paul Schmidt
FEN Member

One of my favorite people in the world, an elderly (and strong willed) Shih Tzu named Diamond, died in my arms before Christmas last year.

Her death was induced despite the veterinarian's suggestion that Diamond be given more time, because the vet really didn't like to end the lives of animals.

Diamond had lived deaf and blind for quite some time, as well as more than a bit incontinent. The reason my friend Diane hadn't "put Diamond down" was that she had remained largely happy, as amply evident by her enthusiastic tail wagging (most of the time), her sheer delight in scarfing down treats, and encouraging tender cuddling.

Given that her quality of life was still viable, inducing her death made no sense to Diane.

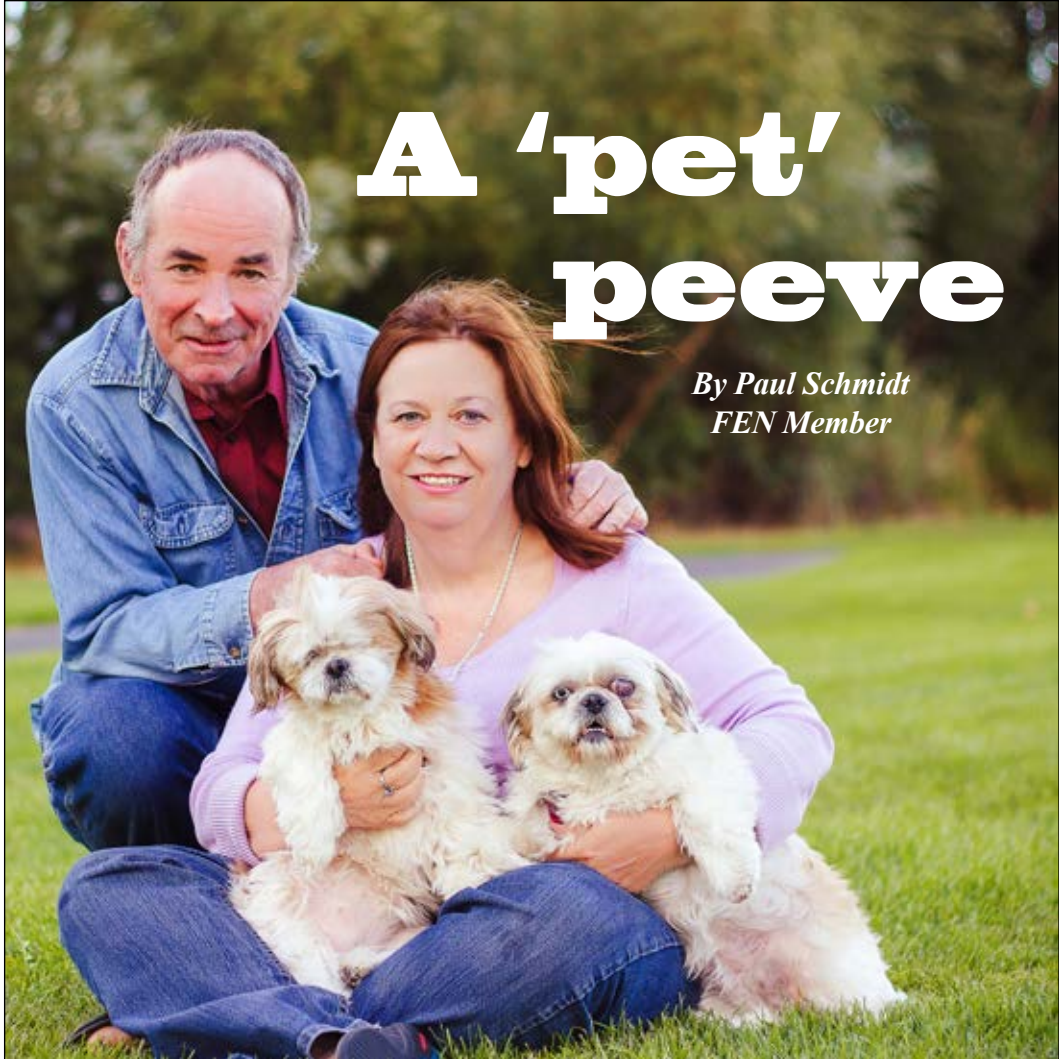
The day finally came when Diamond's happiness died, her little lungs filling with fluid, apparently from pneumonia. Being the force of nature that she was, she resisted the droppers of an oxygen supplement with what strength she had – and even tore off an oxygen mask at the vet's.

This wasn't surprising. Throughout her 16 years, Diamond had been highly proficient at wiggling out of harnesses. I called her the Harry (*ah, Harriet*) Houdini of the canine world!

But this is not just about a wonderful dog and her death. It is about death in general and the timing of it.

When Diane first expressed interest in euthanizing Diamond as an act of mercy, since this little dog could no longer breathe, the vet had said, "Let's give it another 24 hours."

Courageously, Diane didn't wait nearly that long and insisted on proceeding with Diamond's



Paul Schmidt with Diane Justus and pups Diamond (right) and her sister, Spots.

... there's generally no shortage of salespersons offering false hope of recovery.

exit – waiting longer would have been entirely about placating the veterinarian. An induced exit was clearly in Diamond's best interest.

Not always, of course, but much too often, death for we *Homo sapiens* (like for our four-legged friends and members of *Canis lupus*) approaches by degrees, whether or not we are paying close enough attention to understand it. And as those degrees play out, there's generally no shortage of salespersons offering false hope of recovery.

Even so-called "spiritual" folks often rail against self-chosen euthanasia, equating it darkly to what they have become deeply conditioned to interpret as murder-by-suicide.

The question arises: Does this problematic societal bias stem from a fundamentalist interpretation of religion and its "moral" hypnotic power?

The answer is yes, but only in part. There are

PET continued on next page

Unmasking the protestors (stealing a battle cry)

By Janis Landis, FEN Board Member

You watch the news. There's a rally taking place, with a woman holding a sign that says, "My body, my choice." Is it from a reproductive-rights march? Is it from a Medical Aid in Dying rally?

Guess again. It's a protest against wearing a face mask.

It's being held up at a rally organized by conservative anti-choice, anti-DWD groups. The protestors are telling the government that it has no right to require citizens to help stop the pandemic.

If they wish to take the risk and get COVID-19, that's their choice. Of course, the EMTs, and hospital personnel may say that decision affects them. People at risk, who may catch the virus from these folks, may also disagree.

Reasonable people can, and do, disagree on the next steps to deal with the virus. A person can be pro-lockdown, anti-lockdown, or somewhere in between. But this slogan has captured an intense belief about freedom from government coercion.



These protestors believe that government has no right to protect public safety if it means requiring a mask. Yet they do believe government has the right to tell desperately ill, suffering individuals when and how they can die.

We need to harness this energy. Our movement has always taken it as a given that there is an immense divide between "us" and "them" – the conservative movement that is often in opposition to our general political philosophies. Perhaps we need to recognize that there is common ground. Perhaps this protest indicates there is a common language in resentment of government "overreach."

Yes, our movement is about ending suffering. It is about the right to make decisions about our end of life. But if wearing a mask can bring out hundreds, perhaps thousands of individuals to protest, surely we can engage some of these same people in protesting the "nanny state" overreach in invading the most personal aspect of our lives: how and when we die.



PET *continued from prior page*

many atheists and agnostics who would also see us tough out our death (or the death of a loved one) to the very end, fighting like hell!

Was it German philosopher Friedrich Nietzsche who made famous the rigidly stoical saying, "What doesn't kill you makes you stronger"?

There are certain situations in which Nietzsche is likely correct in his insistence on life's will to power as an answer to battling deep adversity, including health – giving up too soon can be a big problem and often is.

On the other hand, fighting that which is inevitable can be an even bigger problem. We can say with certainty that dread diseases like long-endured terminal cancer and deep dementia (to name a few) are hardly guaranteed to make one stronger.

On the contrary, they are much more likely to make you weaker and increasingly miserable, rendering you and those around you much, much worse off than choosing an intelligently pre-planned exit. As FEN advises, it's arguably best to confront

future potential choices on life and death when we are hopefully healthy or at least cogent, rather than waiting for the day when we aren't.

It's as the Queen states in Lewis Carroll's *Through the Looking Glass*: "It's a poor sort of memory that only works backwards."

The day I picked up Diamond's ashes for Diane, the clerk at the clinic tried to be consoling: She looked into my eyes with the best intentions and said, "Putting a pet down is one of the hardest things a person ever has to do."

Harder than enabling useless suffering of someone you love?

Nothing in me wanted to correct or contradict this sweet person, but I found myself replying frankly: "In this case, it wasn't *the hardest thing*. Diamond was suffocating to death."

The woman paused, but only for a moment, then simply said, "Yes she was."



How I want to die

By Brian Ruder, FEN President / Senior Exit Guide

From my first call to “Sara” as a Senior Guide, I knew she was special, and working with her would provide me with an exceptional experience.

She was 90 years old and had been a very active and successful artist. Sara was quite articulate, had a sense of humor, and was certain that she did not want to live the way she was being forced to at the time. She was wheelchair-bound and required care for 12 hours a day.

She hated being dependent!

She told me that her children loved her and understood her desire to die, rather than live the way she was. She asked me to contact her son, who was her health-care surrogate. When I did, he said that the other three siblings wanted to participate, so we scheduled a number of conference calls to discuss exactly what would happen and the timeframes for each step.

After three or four calls, we arrived at a date about two weeks out. When I confirmed with Sara, she was excited, although she wondered why the date was so far away. She had wanted to die for some time.

On the day of her death, all her children and a number of grandchildren came together in her daughter’s home. Two of the grandchildren flew in from out of town. They started the celebration around 1:00 in the afternoon. They had fruits, cheeses, wine, cakes, and other food and drinks set out around the home.

After eating a little, Sara retired to a small bedroom, and for the next three or four hours, all the family took turns spending time with her, remembering old times and saying goodbye.

When FEN arrived, I could sense the love and energy in the room. The children were all emotional, but loved being together for this very solemn moment. The other guide and myself just joined in the discussions, meeting

each person with hugs and appreciation. After 45 minutes, we were told that Sara was ready to see us – she had just finished her last goodbye.

I told her how wonderful her family was and that she did not have to end her life today, as we could come back anytime. With her very strong eyes, she looked at me and said, “I have said all my goodbyes and don’t want to do that again.”

While there was crying and sadness, there was so much more love and happiness that Sara had died the way she wanted ...

We did the education piece of our service, and when everything was done, the entire family decided they wanted to be present when Sara passed. When Sara was comfortable, she looked at her family and said, “I love you,” and she died in the next 20 minutes.

While there was crying and sadness, there was so much more love and happiness that Sara had died the way she wanted, and the family could be there to share the event.

We recited a short poem the children had written, hugged, and all looked at each other and knew we had all just experienced something very special.

As I left the home, I knew that this was the way I want to die, if I don’t die naturally. I want time for my friends and family – to prepare them emotionally – and to think of what memories they want to share.

I want to have toasts of champagne with cheese and fruits. And I want everyone there to feel the love and energy that I experienced being with Sara and her family that night.



THE BACK PAGE

A COMPENDIUM OF RIGHT-TO-DIE WORLD NEWS

United States

A state judge has dismissed a lawsuit challenging the Medical Aid in Dying (MAiD) law enacted a year ago in New Jersey.

Rabbi Yosef Glassman and pharmacist Manish Pujara argued the law “legalizes murder,” and that no doctor should be required to do anything to help carry it out, including releasing a patient’s file.

The law allows doctors and pharmacists to refuse to cooperate with a terminally ill patient’s request to die. But doctors who opt out are obligated to relinquish the patient’s file so another physician can be found, ruled state Superior Court Judge Robert Lougy.

The state Attorney General’s Office asked the court to dismiss the case because neither Glassman nor the pharmacist Manish Pujara who joined the lawsuit had legal standing to challenge a law that did not affect them.

Canada

The COVID-19 outbreak has forced a Montreal man who was instrumental in challenging the country’s assisted-dying laws to hasten his own death.

Jean Truchon received Medical Aid in Dying (MAiD) in April, almost 11 weeks ahead of his original plans. He had hoped to enjoy his last months with friends and relatives, but the 51-year-old resided in a long-term care center that had a case of coronavirus and was not allowing visitations.

Truchon and another incurably ill Montrealer, Nicole Gladu, were co-plaintiffs in a civil suit filed in 2017 that challenged Canadian laws that disqualified patients who were not near death from accessing MAiD.

Australia

The cross-party Health Committee of the Queensland Parliament has recommended passage of a Voluntary Assisted Dying (VAD) law, similar to those now in effect in the Australian states of Victoria and Western Australia.

Chair of the Clem Jones Trust, David Muir, said ideally VAD laws should be drafted and debated in the remaining months of this Parliament and not ignored until after the October 2020 state election.

“Around 80 percent of Queenslanders support

VAD laws, and experience elsewhere shows the mere fact such people know they can seek access to VAD offers a palliative effect, even if they end up not taking advantage (of assisted dying),” Muir said.

Queensland convenor of Doctors for Assisted Dying Choice, Dr. Sid Finnigan, said the Health Committee had acted on the evidence presented to it that overwhelmingly supported Voluntary Assisted Dying.

The Netherlands

The Netherlands’ highest court ruled in late April that doctors can carry out euthanasia in patients with advanced dementia – if the patient has earlier made an Advance Directive.

The case before the Supreme Court revolved around a district court’s acquittal last year of a doctor who in 2016 carried out euthanasia on a 74-year-old woman.

Euthanasia cases among people with advanced dementia are extremely rare: At the time of last year’s trial, there had been fewer than 20 cases since the procedure was legalized in 2002.

England

Sir Keir Starmer, who was the UK Director of Public Prosecutions in 2009, when the Crown Prosecution Service (CPS) announced for the first time the criteria for prosecuting persons who assist a suicide, has been elected leader of the Labour Party in Britain.

Labour is not in power in the Westminster parliament, but if and when the subject comes up again (as it has periodically since 1936), there may be a sympathetic voice.

Following are the latest data on assisted suicide in England & Wales.

From April 1, 2009, through January, 156 cases were referred to the CPS by police as assisted suicide. Of those cases, 105 were not prosecuted, and 31 were withdrawn.

There are currently four ongoing cases: three of “encouraging or assisting” suicide have been successfully prosecuted; one was charged and acquitted after trial in 2015. Nine cases were referred for prosecution for homicide or other serious crime.



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I WANT YOU TO HELP US MAKE NEW RTD LAW!

Advance Directives intended to protect our end-of-life wishes are sometimes ignored. FEN has an outreach initiative planned to use a new directive that will protect those wishes when a patient does not want to be force fed – *even if suffering from dementia.*

We need a test case to establish a legal precedent – and we'll litigate *pro bono* if you believe in the cause and are willing to help.

Read the articles inside and the new directive in this Special Edition of the FEN magazine.