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FinalExit NETWORK

Magazine

MEMORY LANE:

Navigating Dementia

From the Executive Director

In this issue, we share our vision and dedication to addressing one of the most pressing and complex issues of our time: dementia. In this column, I want to shed light on Final Exit Network's (FEN's) response to the critical need for dementia research and the profoundly sensitive yet essential conversation about the right to die for those facing a dementia diagnosis.

Dementia, an umbrella term for a range of neurodegenerative conditions, including Alzheimer's disease, impacts millions of lives worldwide. It robs individuals of their memories, personalities, and independence, and places immense emotional and financial strain on families and caregivers. The statistics are staggering: according to the World Health Organization, around 55 million people globally suffer from dementia, with nearly 10 million new cases every year. By 2050, this number is expected to triple.

As you can imagine, dementia, with its progressive and irreversible nature, presents a unique challenge in the right to die movement. Many individuals fear the loss of dignity and autonomy that comes with advanced stages of the disease, leading them to consider end of life options.

The family of John Smith chronicles their journey following his dementia diagnosis and eventual exit in our recently released FEN video series. I hope you will take the opportunity to watch this powerful, poignant story on our YouTube channel. You can access it from our homepage at www.finalexitnetwork.org.

Throughout this issue, we will highlight the important research FEN is sponsoring to better understand how Americans think about choice in dying in early-stage dementia, when people are still competent. It will also allow an opportunity to share the experiences of those faced with a dementia diagnosis, their families, and the volunteers who work with them as they navigate the limited window of opportunity to take control over their life and their death.

Our goal is to ensure that every individual has the information and ability to make informed decisions about their own life and death, free from suffering and with the utmost respect for their wishes. We invite you to join us in this important dialogue, to push society toward honoring choice in dying, and to help build a future where dignity in dying is recognized as a fundamental human right. Together, we can create a society that respects and upholds the intrinsic value of each individual's journey, right to the very end.

With gratitude,

Mary Ewert

Mary Ewert
Executive Director

IN THIS ISSUE

From the Board President

I believe dementia, and especially Alzheimer's, is one of the most serious medical issues facing our aging population, and that is why we are focusing on dementia in this issue. Much money is being spent trying to find a cure and the best ways to provide care for those with a dementia diagnosis, but little effort is being made to educate people on the choices they have to end their life before they lose capacity. Social norms tend to make people feel there are no good choices, but of course there are. Final Exit Network has been educating people diagnosed with dementia on their options for 20 years. Over 10 percent of FEN clients using our service have early-stage dementia.

The conundrum: current medical aid in dying laws require that a person be within six months of dying to qualify, but of course a person with dementia is not competent in that window of time, so cannot qualify. A person with Alzheimer's can live for many years in a demented state and cause an economic, mental, and physical strain on their loved ones, as they require special care that can cost over $10,000 per month while their families see the person they remember slipping away.

As a society, we have a difficult time talking about dying before we must, especially when the person has dementia. Yet most people I know say that they do not want to live incapacitated by dementia. People should understand their choices for ending their life before losing capacity.

To provide information for these discussions, FEN is proudly beginning a new research project, working with Dena Davis, JD, PhD, to understand how people feel about choosing to hasten their death when diagnosed with dementia. This research has been generously funded by a grant from the Donner Foundation and will hopefully provide a forum for discussion and possibly encourage legislators to consider including dementia in the current medical aid in dying laws. More information on this project is included on page 3.

We all likely know someone who has been affected by a dementia diagnosis. I hope that the content in this issue will shed light on dementia, its effects, and the control one can take over one's life in a seemingly impossible situation.

Sincerely,

Brian Ruder

Brian Ruder
President, FEN Board of Directors

A Dementia Koan

BY LOWREY BROWN

In the Exit Guide Program, we often talk about the window of opportunity, the time during which a person has both the physical ability to assemble and operate the equipment and the mental capacity to make a life-ending decision. Lose either one, and you cannot work with the guide program. I struggle with how best to support clients as they consider an exit date. Though it might sound more koan-like than useful, I often advise clients that there is no right time; there is only too early or too late.

For those facing dementia, I have observed a cognitive divergence that could lead to missing one's cognitive window even when one is still competent. It seems that one can lose a critical level of self-awareness before losing decision-making capacity. In other words, you might still have the capacity to make a life-ending decision, but not be aware that you need to make it. When I describe this possible scenario to clients, they often rush to assure me they are very much aware of their current losses. The catch-22, of course, is how will you be aware of what you are no longer aware?

It was the summer of 2020, the height of the Covid pandemic, and I had flown to California because a client's dementia was progressing faster than vaccine research. As with all my clients, I asked him about what he was thinking. He was a slender, soft-spoken man with a humble self-confidence. As we spoke, he was clear that he had dementia, that he did not wish to descend into the latter stages of the disease, and that he wanted to end his life before that happened. He understood the situation, he understood his options, he understood the consequences of the decision, and he could verbalize his reasoning. In other words, he clearly retained decision-making capacity.

What he was not accurately assessing, however, was his current state of decline. After watching him struggle with the hood-making, I asked him how he was feeling about his exit timing. He would wait until after he could no longer read and write, he told me. He had some projects he wanted to finish. His wife and a dear friend were present for the education, and his wife slowly reached over to touch his arm.

Looking softly but directly at him, she said, "Honey, know that I am happy to care for you and want you to choose what is right for you, but you haven't been able to read for a number of months now."

There was a long pause in which she did not flinch. "I haven't?" he asked.

Not breaking her gentle gaze, she barely but clearly shook her head. *No*.

There was another long pause. I could almost hear the gears in his brain grinding as he integrated what he had just been told.

Finally, he nodded, he too looking straight at her. "Then let's do this."

I might have been holding my breath, afraid to disturb the soft silence that had settled over the room. In their gaze, they reflected each other, like the surface of a still pond and the sky, both so blue it's not clear where one ends and the other begins. I'm not sure if I was more moved by her tender, brutal honesty with him or his deep trust in her, despite what his own mind was telling him.

It reminds me of how vulnerable we are to a twist of biology that can do an end run around our most firmly rooted convictions. Our minds can be our ally, but they can also be our undoing. More accurately, perhaps, they have always been both, and I suspect that a good dose of humility will serve us well as we navigate our end of life journeys.

ko·an

/ˈkōˌän/ noun *(Oxford Languages)* -
a paradoxical anecdote or riddle, used in Zen Buddhism to demonstrate the inadequacy of logical reasoning and to provoke enlightenment.

FEN Sponsors Pioneering Dementia Research

BY MICHAEL KLINGLER, FEN BOARD MEMBER

Dementia is an ever-increasing problem in the United States as the population ages. This is due to a decline in birth rates and higher life expectancies (except in 2020-2021 when life expectancies fell slightly due to deaths from Covid and drug overdoses). According to the Alzheimer's Association, about 6.9 million Americans have some form of dementia now and that number will rise to about 14 million by 2050. Consistent with these statistics, FEN is seeing an increasing number of clients with dementia.

Currently, research by the National Institutes of Health and by drug companies is focused on investigating the causes of dementia and efforts to slow and cure it. Drugs currently on the market are not particularly effective, and it will likely take years before really effective drugs will be available. Meanwhile, the emotional and financial costs of caring for people with dementia will continue to rise, as will the search for solutions to ease these burdens on families and public entities. The choice to hasten one's death in the face of dementia presents a solution for individuals and their loved ones who are so inclined, but little is known about the attitudes of the US population toward it. To find out, FEN is sponsoring research to explore the public's attitudes about hastening death if it can be done in a safe, peaceful, and legal manner.

FEN has secured a generous grant from the Donner Foundation to support the research and is seeking other grants to undertake this initiative. Understanding the need for this body of data, the FEN board of directors will provide funding for the project as well.

The lead investigator for the project is Dr. Dena Davis, retired professor of ethics and religious studies at Lehigh University. She has been a visiting scholar and research fellow at a number of prestigious research institutes, and has conducted two related dementia projects.

The goal of the project is to produce a peer-reviewed research paper for publication in a prestigious scientific journal. The expectation is that the research paper will support right to die groups that advocate for changes to medical aid in dying laws, add to the national discussion about the right to choose, build awareness in dementia patients that they have options, and enhance FEN's reputation in the right to die community.

Spotlight on:
Lead Investigator
Dr. Dena Davis

Dena S. Davis, JD, PhD, is the Presidential Endowed Chair in Health at Lehigh University, where she teaches a variety of courses in bioethics. Dr. Davis received her Bachelor of Arts from Marlboro College, her Juris Doctorate from the University of Virginia, and her PhD in Religion from the University of Iowa.

Dr. Davis was a Fellow in the Department of Bioethics at the Cleveland Clinic and has been a Visiting Scholar at the National Human Genome Research Institute, Arizona State University, and the Hastings Center. She holds an adjunct appointment at Case Western Reserve University's Department of Biomedical Ethics, and is a Faculty Associate in CWRU's Center for Genetic Research Ethics and Law. She is the author of several articles on biomedical ethics and two books, *Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children's Futures* (Oxford University Press, 2009) and *Notes from a Narrow Ridge: Religious Studies and Bioethics* (University Publishing Group, 1999), which she coauthored. A third book, *How Genes Tell Stories*, is in progress.

Understanding Dementia

BY MICHAEL KLINGLER, FEN BOARD MEMBER

A common misconception is that Alzheimer’s disease and dementia are synonymous. In fact, dementia is an umbrella term covering all types of dementia, including Alzheimer’s. Although many types of dementias have been identified, most are quite rare. In this article, we will explore the five types of dementia that account for over 90 percent of dementia cases.

Progression and screening

The progression of dementia disease has been staged from mild to severe. However, recent advances in screening tests, laboratory procedures, brain imaging, and autopsy studies have identified an earlier stage during which there are changes in the brain but no outward disease symptoms. It is unclear whether these individuals would eventually develop dementia symptoms or if they have some protective mechanism delaying or preventing cognitive decline despite the brain pathology.

The five most common types of dementia include:

- Alzheimer’s disease
- Vascular dementia
- Lewy body dementia
- Frontotemporal dementia
- Mixed dementia

While each type has distinct characteristics, there can be overlap in symptoms.

Alzheimer’s disease

According to the CDC, Alzheimer’s is the primary diagnosis in 60 to 80 percent of dementia cases. It is characterized by buildup of amyloid plaques in the brain. Symptoms include memory lapses, forgetfulness, difficulty finding the right words, problems with planning and decision-making, misplacing items more frequently, and in some cases, changes in mood and personality. These deficits become more severe as the disease progresses. Over time, there is difficulty recognizing friends and family members, inability to cope with new situations, restlessness, and repetitive statements and movements. Help is needed with daily activities like dressing, bathing, and using the toilet. Some people will have difficulty swallowing and walking.

In the final stage, there is total dependence on others for all activities of daily living and increased vulnerability to infections and other health issues. The rate of progression varies from person to person, but on average, people live between three and eleven years after diagnosis. Notable personalities who had Alzheimer’s include Sean Connery and Rita Hayworth.

Vascular dementia

Alzheimer’s Disease International estimates that 17 to 30 percent of dementia diagnoses fit this category. Vascular dementia causes cognitive decline and impairment in daily functioning due to reduced blood flow to the brain. As the disease progresses, it can be earmarked by loss of speech and mobility, inability to communicate, and potentially the loss of ability to swallow.

While there is overlap with Alzheimer’s, vascular dementia tends to impact cognitive skills earlier, while in Alzheimer’s the prominent symptom is memory loss in the initial stages. Notable personalities who had vascular dementia (combined with Alzheimer’s) are Glen Campbell and Perry Como.

Lewy body dementia (LBD)

The *Psychological Medicine Journal* reports that approximately 8 percent of dementia cases are caused by the accumulation of Lewy bodies (abnormal deposits of the protein alpha-synuclein) in the brain. LBD causes

Exploring the Most Common Types and Their Impact

problems with attention, multitasking, hallucinations, tremors, and slowed movements. In later stages, the patient has severe cognitive impairment and memory deficits, inability to communicate effectively, loss of ability to walk or smile, and needs full-time assistance for all activities of daily living. There is also the potential loss of emotional control and increased risk of infections like pneumonia.

LBD differs from Alzheimer's in that LBD is characterized by symptoms like tremors, muscle stiffness, and shuffling gait early in the disease course. These indicators are not typical in Alzheimer's until very late stages. Visual hallucinations are very common in LBD, occurring in up to 80 percent of patients. (Hallucinations are much less prevalent in Alzheimer's.) LBD tends to progress more rapidly than Alzheimer's overall. *Medical News Today* reports that the average time from onset to death is five to seven years for LBD. Notable personalities who had Lewy body dementia are Robin Williams and Bill Buckner.

Frontotemporal dementia (FTD)

While there is no individual data for FTD, the Association for Frontotemporal Degeneration estimates that this type of dementia accounts for 10 to 20 percent of dementia diagnoses.

Frontotemporal dementia affects the frontal and temporal lobes of the brain. Typical deficits include impulsiveness, difficulty with communication, and impairment in planning and problem-solving. Many patients develop tremors and have difficulty swallowing. In the final stage, the patient will be bedridden and require round-the-clock care.

While Alzheimer's disease is characterized by early memory deficit, FTD initially presents with language impairments. Memory deficits occur in later stages. Notable personalities who have frontotemporal dementia are Bruce Willis and Wendy Williams.

Mixed dementia

Mixed dementia, such as Lewy body disease and frontotemporal dementia, or Alzheimer's combined with vascular dementia, exhibits symptoms of each disease.

The rate of progression is more rapid and the average time from diagnosis to end of life is typically shorter than patients with only one of the diseases. The UK Alzheimer's Society estimates that 10 percent of dementia cases fit into this category. Notable personalities who had mixed dementia are Norman Rockwell (Alzheimer's and LBD) and Sugar Ray Robinson (Alzheimer's and dementia caused by repeated head trauma).

Dementia cannot be cured, but early diagnosis is crucial both to initiate treatments that may temporarily improve symptoms or to slow progression and, for those who want the option, to plan an exit before losing one's decision-making capacity.

Resources

Dementia is a complex and multifaceted condition that affects millions of individuals and their families worldwide. It brings with it not only challenges to memory, thinking, and behavior but also profound emotional and social impacts. For those living with dementia and their caregivers, access to reliable information, practical support, and community resources is crucial. These are some resources that may be helpful to those navigating the diagnosis:

- Alzheimers.gov
- Alzheimer's Foundation - alzfdn.org
- State Departments of Health
- National Institute on Aging - www.nia.nih.gov

Health “Care” in America

BY JANIS LANDIS, FEN BOARD MEMBER

Our health care system is “sick” and we pay the price.

In many ways, America’s seniors are living their best lives, thanks to extraordinary medical advances, Medicare, and specialists of every kind. We often hear that other countries provide good medical care but limit the availability of cutting-edge treatments or expensive interventions for older individuals.

The United States spends significantly more per person every year on health care, with an average of nearly $13,000 per person spent annually.

Does this translate to a better life expectancy? No. Despite all that the United States spends, it has the lowest life expectancy of any high-income country.

Why is this? Most experts think it has everything to do with the profit-based system that runs more and more of our emergency rooms, hospitals, nursing homes, and even hospices.

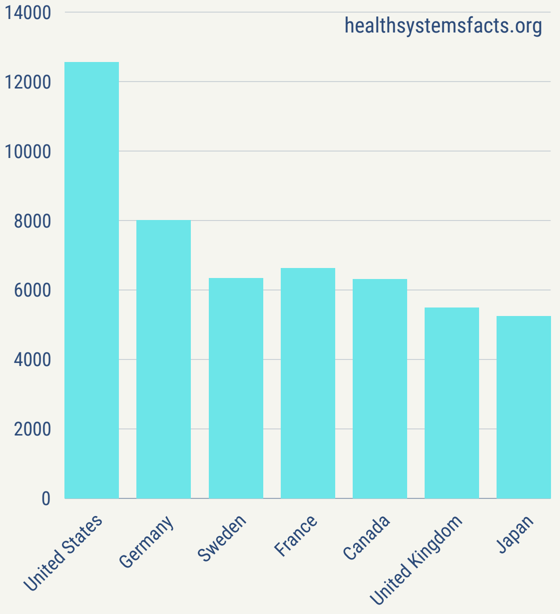
Or as a team of public health researchers put it succinctly, “It’s the prices, stupid.”

Every part of the US health care system takes a chunk of our health care dollars and puts them into the profits column. For example, United Health Group reported $22 billion in 2023 profits, and they are not unique.

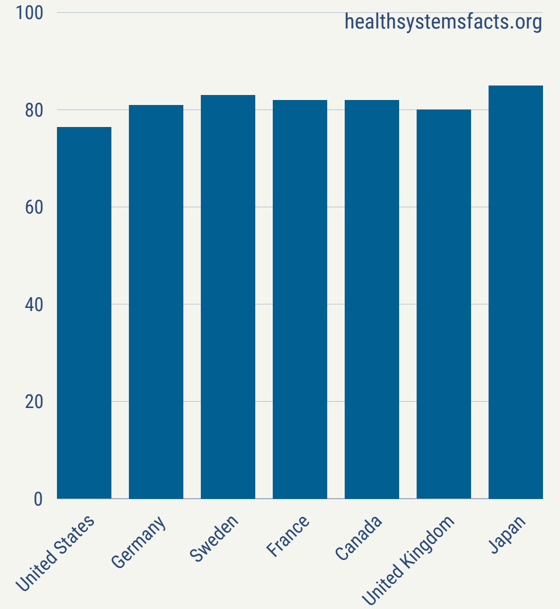
Assisted living facilities currently tend to almost one million Americans. Few of the residents are singing the praises of their “home.” But according to the non-profit Kaiser Family Foundation, half of assisted living facilities earn a 20 percent profit. These rates are maintained by constantly chipping away at the amenities patients were initially provided. In addition, extra charges can include such basic items as insulin shots or a blood pressure check.

What can you do about it? Avoiding assisting living isn’t always an option. But you can and should know your rights. One little-known law ensures your right to know your treatment options and give or withhold informed consent. Information on this law is compiled on the Cornell University Law School‘s website at https://www.law.cornell.edu/cfr/text/42/part-483/subpart-B. It’s worth a look.

ANNUAL HEALTH SPENDING PER PERSON BY COUNTRY



AVERAGE LIFE EXPECTANCY



Medical facilities will seek to add endless treatments, medications, etc., which add to their profits, and possibly extend a patient’s life when death would be a welcome relief. You can say “no.”

Do not hesitate to exercise this right on your behalf or for an individual for whom you are the health care representative.

Many of us would rather our dollars be diverted from increased profit margins to increasing the quality of life for all Americans.

One Family's Journey

DEMENTIA DIAGNOSIS LEADS SMITH FAMILY TO FINAL EXIT NETWORK

Shortly before finding out about Final Exit Network's resources, Catherine Smith and her husband, John, faced a heartbreaking prognosis. John was diagnosed with Alzheimer's disease after undergoing an MRI, a revelation that stirred profound fears within him. John dreaded becoming a burden to his family or losing his autonomy as the disease progressed. The couple found themselves at a crossroads, confronting the harsh realities of Alzheimer's.

Living in Eugene, Oregon, the couple was aware of the state's Death with Dignity Act, which permits terminally ill patients to end their lives with prescribed medication if they have a prognosis of fewer than six months to live. This option briefly provided a beacon of hope. However, Alzheimer's, with its unpredictable trajectory, fell outside the scope of this law.

Facing an unknown future, but blessed with a cherished circle of supportive family and friends, John and Catherine faced his disease head-on with grace, determination to take control when possible, and John's hallmark sense of humor.

After reaching out to Final Exit Network, being accepted into the program, and meeting with exit guides, John planned his final day meticulously, choosing to celebrate his life surrounded by family and friends. He faced his last moments with remarkable clarity and genuine happiness.

The Smiths' experience underscores a critical lesson about end of life conversations. It is vitally important to have these difficult discussions, embracing them as a gift of love and honesty. By doing so, we offer our loved ones and ourselves a path to peace and dignity. For John and Catherine, this meant acknowledging the inevitable and making a decision that aligned with John's desire for autonomy and dignity.

John's story is a testament to the courage it takes to face the end of life with grace. It serves as a powerful reminder of the importance of being loving, clear, and honest about our final wishes, ensuring that our last days are lived with dignity and surrounded by those we cherish most.

As mentioned in the Spring 2024 FEN magazine, Russell Bates, commercial and TV director and a volunteer coordinator for FEN, has created a pair of films in conjunction with Final Exit Network's 20th anniversary. John Smith's story is the focus of one of the films, and we encourage you to watch this poignant, heartwarming piece that chronicles John's journey. A link to watch the video is available on the FEN website: www.finalexitnetwork.org.

Many Thanks


Jay enjoying one of his pastimes, playing the drums.

Five years ago, when FEN needed a new magazine editor, we were extremely fortunate to have Jay Niver volunteer. With his career and expertise in journalism and communications, he was exactly what FEN needed!

Jay completely revised the format, style, and content, and made our magazine a professional product in which we all take pride. Readers have sent many wonderful notes indicating how much they enjoy the magazine over the years.

While Jay is turning over the reins of the magazine to our executive director, he remains steadfast in his support for FEN's mission and plans to remain as an active volunteer serving in other capacities. We are enormously grateful to have had the benefit of his talents and services for these many years.

Thank you, Jay!

ABOUT US

Our bodies are the focus
for as long as we can remember.

We feed them,
and nurture them
and
as younger folks
and graphic artists
urge us...
we exercise
and diet
and cover up the well earned lines
trying to resist the changes
that are inevitable.

And then,

when the goals
become impossible to reach,
and the temptation is to feel
decline has won...

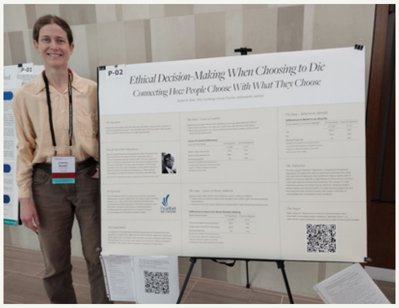
Then, in the morning light,
we wake up...

Perhaps there are other words
for this time in our lives.
Now the body is in charge,
and it is telling us…
"It is time, it is time."

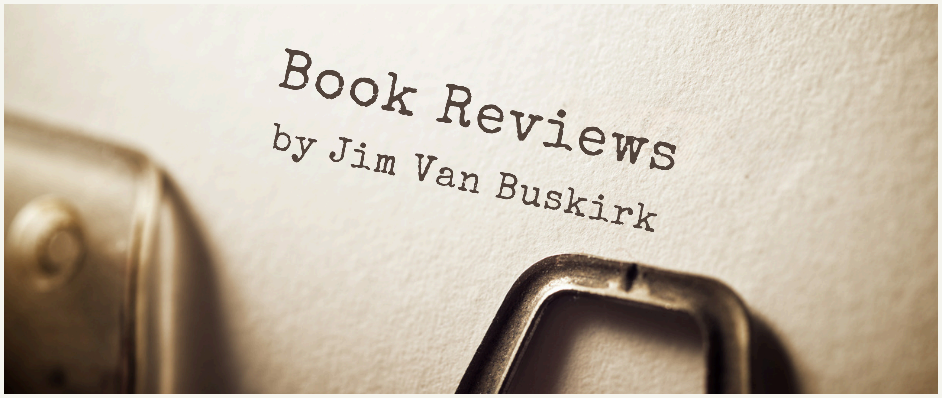
~Barbara Wood Gray
On an achy day in the Fall of life

"Sharing the Song" is available at www.lulu.com/shop

FEN Is Making Its Mark at Conferences

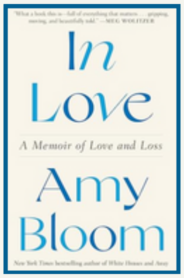


- FEN Exit Guide Program Director Lowrey Brown (at left) recently presented on choice in dying outside the medical model at the International Conference on End-of-Life Law, Ethics, Policy, and Practice on Choice in Dying.
- FEN Executive Director Mary Ewert was selected to present at the 2024 International Death, Grief, and Bereavement Conference in early June at the University of Wisconsin LaCrosse. Her presentation focused on 2023 FEN research study findings.



- Amy Bloom -

In Love: A Memoir of Love and Loss (2022)



This poignant and powerful memoir recounts the author's journey with her husband, suffering from Alzheimer's disease, to Dignitas in Switzerland.

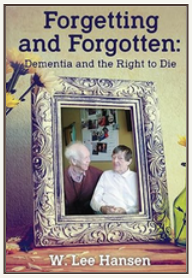
- W. Lee Hansen -

Forgetting and Forgotten: Dementia and the Right to Die (2023)

(This book review was published in an earlier FEN magazine, but because of the topic, we thought it's worth repeating in this issue focused on dementia.)

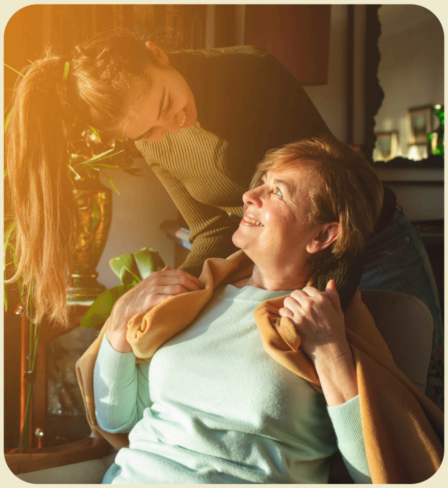
This valuable book is simultaneously a cautionary tale and a call to arms. The author, a professor emeritus in economics, uses his experience watching his vibrant wife's descent into dementia and his expertise in advocacy to create an important contribution to the conversation about dementia patients' end of life options.

Relying on his daily journal entries, he chronicles Sally's ten-year trajectory from 2006 until her death in 2016. Their heartbreaking journey offers remarkable rewards for the reader. Carefully observed details straightforwardly present a clear picture of Sally's deterioration, including depression, repeated falls, alcohol abuse, cognitive decline (distinguishing between dementia and Alzheimer's), agitation, paranoia, and the challenges of multiple care facilities, medical professionals, and medications. While emphasizing that each person's experience is unique, Hansen's willingness to share his intimate observations is a profound gift.



The book's final third offers a toolbox of very helpful information about how to advocate for oneself, one's loved ones, and more broadly, to change the current legal/medical situation regarding right to die options specific to dementia. A few minor mistakes mar the otherwise impeccable guidance, including confusing the roles of Final Exit Network and Exit International.

Kudos to Hansen for employing his painful personal experience to produce a poignant memoir and a powerful political manifesto.



Advance Directive for Dementia Care

FEN's Advance Directive (AD) for Dementia Care was developed to prevent dying people from being kept alive against their wishes, long after dementia has eradicated their former selves.

FEN's website features a downloadable template to complete and add to an individual's current advance directive documents. Before signing the document, the user must have a separate general purpose AD in place, along with an appointment of a health care surrogate. The AD, appointment of a surrogate (which is often within the AD), and the supplemental advance directive should be kept together and given to the individual's healthcare providers for placement in their permanent medical records.

More information is available at finalexitnetwork.org/advance-directives-for-dementia/

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