American College of Emergency Physicians
August 2024

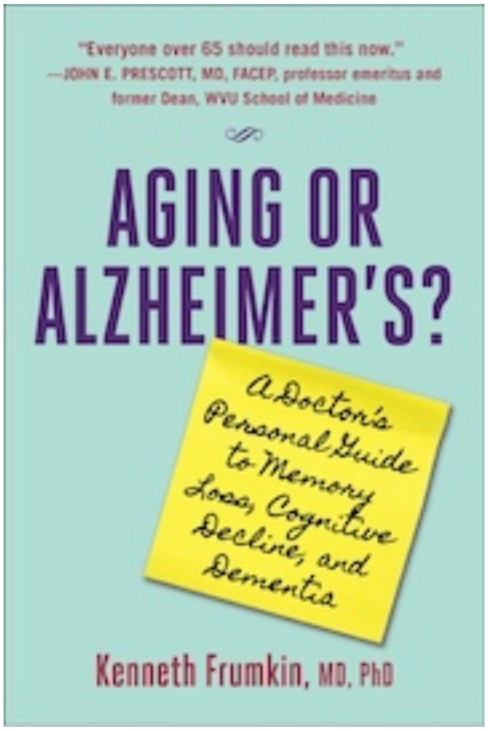
The Explorer

Exploring Retirement ACEP Section Newsletter

Dementia Edition, Debra Perina, MD, FACEP Topic Editor

Is It Aging Or Alzheimer's?

Kenneth Frumkin, PhD, MD, FACEP



This book is currently in press.

Available November 2024.

Preorder the book:

http://agingoralzheimers.com/

"Two of three Americans will experience cognitive impairment by the age of 70. But is it natural age-related forgetfulness or the early indication of Alzheimer's Disease or other types of dementia? How worried should older people—or their families and friends—be about their memory loss? And what happens next?"

"Aging or Alzheimer's? explains what is currently known about the challenges to memory and cognition that come with longevity. Dr. Frumkin describes the progression of Alzheimer's disease and other dementias; discusses when to see a doctor and what to expect from the visit; weighs the pros and cons of available tests, treatments, and research; shares personal and passionate tips for coping with decline; and gives the best ways to preserve cognitive health."

Why me? Why this book? Why now?

An experimental psychologist by undergrad and graduate training, I started the research that became this book at the age of 70, after retiring from a 36-year career in emergency medicine. With increased time for family, same-age friends, and a lot of introspection, I began to question my own memory failings and started recognizing them in my peers, giving rise to a strong and *very personal* need to understand cognitive decline and dementia.

Even after being pronounced "worried, but well" and "normal for age" by two eminent neurologists, my day-to-day difficulties and the unease they generate remained. With no initial agenda other than finding answers for me, I reviewed more than 1,200 scientific papers about memory loss, cognitive decline, and dementia. The goal was to educate myself, as I had done countless times on behalf of my patients, with many of those prior knowledge-quests being published in EM journals and medical news magazines.

Continued on Page 3

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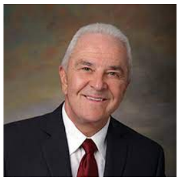

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Announcements: RELEVANT in Vegas

Dear Explorers,

As we bask in the sun of late August, some of us are still bound by school year calendars, others are snowbirds planning to migrate south in the coming months. Regardless of your itinerary, our worlds tend to get busier after Labor Day. This also represents the time when ACEP gears up for the annual Council meeting and ACEP24. That means making plans to head to Las Vegas, where I hope to see as many of you as possible.

If you are planning to attend, here are some important times to put on your calendar. Beware, there's LOTS of overlap on Sunday (9/29) afternoon.

Council is Friday & Saturday, the 27th & 28th. We will try for a September Zoom call to discuss resolutions that directly impact our Section or that we would have valuable insight into. The candidates for officers and Board members is as strong as ever. This year, our Section Councilor is our newsletter editor Pam Bensen. Many of us have a seat on the floor from previous service to the College, so we will also be on the Council floor.

Trying to stay relevant, and at the request of Jim Antonori (stepping down after over 30 years), I will moderate the Small/Medium Chapter's Caucus. Stay tuned, this is why some of us still stay very engaged with ACEP.

September 29th, the annual meeting of the Exploring Retirement Section will take place from 4:00-6:00 pm in the Mandalay Convention Center. We are obliged to elect our officers, for the first time, for a two year term (Chair, Vice Chair, and Newsletter Editor). Please let Julie Wassom know if you would like your name submitted for any of these positions. After other business, we will have panels to discuss Dementia and Volunteerism. If you have an inspirational insight into either topic, PLEASE let me know. I am particularly interested in recruiting for the Volunteerism panel.

Our own Deb Perina will be involved in the Dementia panel but will have to sneak out of our meeting early to accept the Wiegenstein Award College at a separate location. We will adjourn the meeting at 6:00 to start the Section "Pub Crawl" that runs till 8:00 pm.

We will host a "Pub" site, presumably in the same room as our meeting. I am still seeking photos from an exotic or important location you have "Explored" recently. We hope to make our booth so interesting that it gets lots of interest and traffic. Many of us will then need to rush across the casino to the EMF VIP reception, so wear comfortable shoes.

If there are other topics you want to discuss at our Section meeting, I will leave time for open discussion. Please bring a "How I'm staying relevant" story, just in case I call on you.

I'm eager to see everyone as we are strive to meet the needs of hearing and mobility challenged members.

Stay healthy, be sure you've registered to vote, travel safely, and

REMAIN RELEVANT!

Steve

Introduction: Dementia The Long Goodbye

Debra Perina, MD, FACEP
Guest Editor

It is estimated that 1 in 10 Americans 65 or older have some form of cognitive impairment and are ultimately diagnosed with dementia. Given this statistic, it is likely everyone reading this newsletter has either had personal experience with or knows someone with a loved one who has dementia. Or, Maybe you're feeling its early effects yourself.

Dementia is an insidious thief, slowly stealing from individuals that which made them who they were. Dementia not only affects the diagnosed individual, but it also slowly deprives family members who are forced to stand by and watch as it steals their loved one, who loses memory and function slowly over years. No wonder it has been called "the long goodbye."

This edition of the newsletter looks at dementia from several different angles: early assessment tools, communication challenges for caregivers, dementia hospice care, and the phenomenon of terminal lucidity. It also contains deeply personal stories from those recently diagnosed, family members who lost loved ones to the disease, and the personal journey of a primary caregiver for a loved one with dementia.

These articles serve as an entry point for information and, hopefully, provide guidance on where to look for additional readings and resources.

Dementia touches all of us as an aging community. It's important to understand you are not alone! Support is out there.

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Is It Aging Or Alzheimer's?

continued from page 1

The more I read, the more questions arose, and the deeper I sank into the medical literature. It should be no surprise to learn that sixty-five thousand citations with "Alzheimer's disease" in the title were listed in the National Library of Medicine database as of February 2023, with new publications arriving at an average rate of 476 per month.

The hoped-for "needles" in such a haystack are the multi-authored collections of expert reviews organized by national or international societies, or agencies. That sort of consensus integration of fresh information with prior scientific work occurs at roughly 10-year intervals and is known as the "Decadal Survey" method. It was established by the National Academies "to identify lines of research with the greatest potential impact over a 10-year period."

Research moves forward constantly, but it is those consensus reviews by national and international organizations that underlie common teaching and practice, at least until busy docs catch up with the next "decadal" cycle. Since the most recent of these consolidations of Alzheimer's disease research were published between 2015 and 2019, I had essentially created a timely new summary for myself to share with my readers.

Appropriately subtitled *"A Doctor's Personal Guide to Understanding Memory Loss", Cognitive Decline and Dementia* fills more than 340 pages and is supported by 535 references. Fifty-seven percent of those references date from 2020 or later. For release in November 2024, one can read this book or wait 5 or more years for the latest "decadal' reviews to appear, and a little longer for your doctor to get around to reading them.

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5-Minute Cognitive Test Helps Detect Dementia in Primary Care

Key Takeaways:

- The 5-Cog assessment tool helped improve dementia-related care in primary care patients.
- 5-Cog tripled the odds of identifying which patient would receive a dementia-related intervention within 90 days.
- The tool takes 5 minutes to administer and tests memory recall, cognition, gait, and symbol-matching.

A recent randomized controlled trial showed that a quick cognitive assessment tool, 5-Cog, improved dementia-related care in primary medicine. Compared with a control intervention, the 5-Cog system tripled the odds of identifying patients who would receive a dementia-related intervention, defined as either a new diagnosis of dementia or mild cognitive impairment; ordering of diagnostic imaging, tests, or prescriptions; or a specialist referral within 90 days of the test (18.5% vs 6.8%, P<0.001), reported Joe Verghese, MBBS, MS, of the Albert Einstein Medical College in the Bronx, New York.

According to the authors, dementia is often undiagnosed or untreated when diagnosed in primary care. Primary care cognitive tests can be long or require specialized personnel. An easy to administer cognitive detection tool paired with a clinical decision support could improve dementia diagnosis and care. Another challenge is that many cognitive tests were developed in white populations and thus do not adequately account for cultural differences or health inequity.

The 5-Cog tool takes 5 minutes to administer and combines three metrics testing memory recall, cognition, gait, and the ability to match symbols and pictures. The tests are quick and not affected by reading levels, ethnic or cultural differences among patients. The tests can also be administered by non-physicians as a screen during the check in process. When the 5-Cog test was coupled with a decision tree embedded in a patient's EMR it was even a more sensitive tool. Researchers enrolled 1,201 older adults presenting with cognitive concerns at an urban primary care clinic (May 2019 to September 2022). Mean age was 73, 72% were women, and 94% were Black, Hispanic, or Latino. Overall, 599 participants were assigned to the 5-Cog group and 602 to the control group.

Follow-up at 90 days showed that, compared to the control group, patients who had a positive 5-Cog test were three times likelier to benefit from improved dementia care, including being diagnosed with a new mild cognitive impairment or dementia, being referred to specialists, and receiving medications. Dementia care occurred in 43.8% patients with positive 5-Cog results and 1.4% with a negative 5-Cog. New diagnoses of mild cognitive impairment (7.3% vs 0.8%) and dementia (3.5% vs 1.5%) were higher in the 5-Cog arm than controls. The 5-Cog group had more laboratory tests (OR 7.64), imaging tests (OR 4.80), and specialist referrals (OR 2.38) for cognitive indications than the control group (all P<0.001).

Study limitations: It was at a single center and involved only patients with memory concerns, not asymptomatic older adults. A multi-center study involving undifferentiated older adults is currently in progress.

Below is a link to the 5-Cog test and instructions on how to administer it.

file:///C:/Users/dgp3a/Downloads/Five-MinuteCognitiveTestasANewQuickScreeningofCognitiveImpairmentinTheElderly.pdf

More information about this and other rapid assessment tools for early dementia:

https://www.nih.gov/news-events/news-releases/new-clinical-assessment-tool-improves-dementia-care-actions-primary-care-patients

https://www.medpagetoday.com/neurology/dementia/110551

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What If You Personally Received An Alzheimer Diagnosis?

When noted neurologist Dr. Daniel Gibbs noticed changes in himself, he became his own patient. After consulting other neurologists and receiving a personal diagnosis of early dementia, he knew he had some hard decisions to make. How to cope with the inevitable progression he knew so well? How to make the most of what lucid time he had left? What could others learn from his journey and how to best document it?

He chose to write what is essentially his journal – a book about living with Alzheimer disease, *A Tattoo on My Brain*, which was published 3 years ago. A short documentary based on the book with the same name is available for streaming on Paramount Plus. Dr. Gibbs also recently published a collection of essays entitled *Dispatches From the Land of Alzheimer's*.

Over the ensuing 3 years, his cognitive ability declined but at a very slow pace. As the documentary shows, he can no longer remember the 5 words his neurologist told him only a few minutes earlier. His wife often retraces his steps ensure he remembered to turn off the lights or water.

There is a misconception that Alzheimer disease is rapidly progressive but that's just not true. The definition has been broadened to include Alzheimer disease which is progressive to Alzheimer dementia. Researchers found that brain pathology in Alzheimer disease begins about 20 years before any cognitive impairment. The first noticeable stage, mild cognitive impairment, wasn't even recognized and was not even called Alzheimer disease.

What lifestyle changes can help slow progression? The intervention with the most data is aerobic exercise. Running is great, but just walking works as well. Any aerobic exercise helps slow progression. Although the data is not as robust, staying intellectually and socially active seems to help as does getting enough sleep. Less than 7 hours of sleep per night increases Alzheimer risk.

In addition, all the cardiovascular risk factors increase the odds of Alzheimer's; what's bad for the heart is bad for the brain. Alcohol is controversial but the pendulum is swinging back toward recommending no alcohol.

Reading books also stimulates cognitive abilities, although Dr. Gibbs found that books with progressively less complex plots and fewer characters are needed as the disease progresses.

What would he tell someone newly diagnosed with Alzheimer disease? "Watch out for apathy." As Alzheimer's progresses it is harder and harder to follow multiple conversations which all blend together. As a result, one tends to isolate and avoid crowds or gatherings becoming essentially antisocial as it becomes increasing uncomfortable to socialize. This is part of a change in the brain that is not exactly the same but is a close relative of depression. He notes that taking an antidepressant helped.

Dr. Gibbs was recently interviewed by JAMA Medical News about his health and the misconceptions about Alzheimer disease. Read the full interview with Dr. Gibbs at:

A Neurologist Learned He Had Alzheimer Disease 8 Years Ago—Here's What He Wants People to Know | Neurology | JAMA | JAMA Network

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Dementia Is A Marathon, Not A Sprint!

Don't lose site of the fact that dementia is a marathon, not a sprint. You can push through anything, medical school, residency, a grueling ED shift, deployment, boards, even labor because there is a concrete end that you can anticipate in minutes, hours, days, months, or even years. Dementia deprives us of that luxury. Dementia is forever, you must have a plan B.
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Hospice Care for Dementia?

Traditional hospice falls short of meeting end of life needs for those with dementia. Hospice brings a multidisciplinary team to where a patient lives to maintain their physical and psychological comfort so that they can avoid the hospital as they approach the end of life. Hospice is not the same as palliative care, which is a multidisciplinary team that sees seriously ill patients in a clinic or hospital to help with symptoms, distress and advance care planning.

According to the palliative care society, only 12% of Americans with dementia ever enroll in hospice, and when they do one-third are near death. This is in stark contrast to patients with cancer, where patients over 60 enroll in hospice 70% of the time. The underuse of hospice by dementia patients likely has more to do with how hospice is structured and paid for in the U.S. rather than patient preference.

In the U.S., most hospice stays are paid for by Medicare, which dictates what hospice looks like, who qualifies for hospice and what services hospice provides. Medicare's rules and regulations make it hard for dementia patients to qualify for hospice when they and their families need support the most – long before death. In Canada, where hospice is structured entirely differently, 39% of dementia patients receive hospice care in the last year of life.

Hospice opened in the U.S. in 1974. Medicare coverage began in 1983. By 1985, end-of-life care costs, mostly for patients with advanced incurable illnesses who died in the hospital after spending time in the ICU, were the fastest-growing part of Medicare's budget. Congress then formalized Medicare's hospice payment structure believing hospice would give seriously ill Americans an alternative to a medicalized death and help control costs.

Medicare coverage allows hospice to support families and follow patients whether they live at home or in a nursing home. In exchange, people enrolling in hospice agree to forgo other care, such as hospital admission or seeing specialists. This is a barrier for life-limiting illnesses, such as dementia, since ongoing treatments may slow disease progression or improve quality of life. Researchers found life-limiting illness patients are half as likely to enroll in hospice.

Psychiatrists and geriatricians who treat dementia, and psychologists, nurses, and social workers who support them, are invaluable to families struggling to manage a dementia patient's disruptive and sometimes violent behavior. The dementia care team adjusts and rotates medications (sedatives, antidepressants, antipsychotics, anti-epileptics, etc.) to help patients experience less anxiety, agitation or depression as their memory fades. Medication adjustments are normal for dementia patients, who are particularly prone to the side effects of agitation or drowsiness.

Specialized dementia teams are difficult to exchange for hospice care which is provided by generalists following a protocol with a short list of approved medications. However, this is exactly the decision caregivers and patients with dementia face, if Medicare is going to cover hospice costs.

Even when dementia patients and their families are willing to forgo specialists and hospitalization, they are still unlikely to meet Medicare's stringent hospice criteria, which is limited to patients expected to die within six months. Death cannot be predicted with any accuracy for dementia patients, thus the conundrum.

Medicare's criteria require people with dementia to be bedridden and dependent on others for help with toileting, transferring, bathing, walking and personal hygiene. They must be incontinent, minimally verbal and have a terminal complication of dementia such as aspiration pneumonia, recurrent urinary tract infections, significant weight loss, or bed sores. As these conditions typically occur only in the most advanced stages of dementia, people are less likely to qualify for quality hospice home care.

Most importantly, Medicare's hospice benefits do not provide dementia patients and families the support they need most – hands-on care. What they do provide is a bath aide a couple of times a week and home health aides for brief periods to give caregivers a break. Monitoring, hand-feeding, repositioning, ambulating, toileting, medication administration and wound care are left up to caregivers.

Dementia patient's families face a difficult choice, sacrifice personal well-being and livelihood to care for a loved one at home; hire a professional home health aide at $30-$50 an hour; or place the loved one in a nursing home. And nursing homes are paid out of pocket unless the patient qualifies for Medicaid. Given these impossible options, it is easy to understand why most dementia suffers are not in hospice and care-giving burdens fall primarily on family members.

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Olive Oil Helps Women with Dementia

"Higher olive oil intake was associated with a lower risk of dementia-related death in a large longitudinal study…significant for women, but not men. Olive oil consumption may lower dementia mortality by improving vascular health…"

https://www.medpagetoday.com/neurology/dementia/109986

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Notes to Self:

You cannot reason someone with dementia back to reality.

Don't sit on the floor without a plan on how to get back up.

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How Did It Start?

When young, my body enticed you.
I wanted to be loved for my brain.

Decades ago, you glimpsed me,
Dressed in moonlight and were drawn.

Face to face in sunlight, introductions made,
Banter enhanced first impressions.

You taught me to be loved for my body,
As you learned to love me for my brain.

Together we twined our DNA into family,
A stew of bodies and brains satisfying all.

We loved, we grew, we stretched, we sustained,
We did what it took, together.

The shift, the rift, the end, the beginning,
Whatever. It came with a silent tear.

You held me gently,
As I whispered in your ear

"*I can't find my way home.*"

"Please love my body,
My brain is no longer here."

Now, when we're together.
You're all alone.

--Anonymous Pennie

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Treatable Condition Misdiagnosed as Dementia in Almost 13% of Cases

"Patients with dementia may instead have hepatic encephalopathy and should be screened with the Fibrosis-4 (FIB-4) index for cirrhosis, one of the main causes of the condition, new research suggests."

https://ma1.mdedge.com/neurology/article/270064/alzheimers-cognition/treatable-condition-misdiagnosed-dementia-almost-13?ecd=WNL_EVE_240725_mdedge&uac=107208EG

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Communication Challenges in Dementia

Caring for a loved one with dementia poses many communication challenges for families and caregivers. People with dementia find it progressively more difficult to remember things, think clearly and communicate with others. As dementia progresses, mood swings, personality, and behavioral changes occur. Communication becomes incrementally more challenging.

Some noticeable changes in the person with dementia (individual) include:
- word finding difficulty,
- use of speech that does not make sense,
- inability to understand what you are saying,
- grasping only part of what you are saying.

Thus, words can be helpful and uplifting, but also hurtful and frustrating to the individual depending on the situation.

Basic Do's when communicating with someone with dementia:
- Be calm, patient, cheerful and reassuring.
- Practice 100% forgiveness, memory loss progresses daily.
- Speak slowly and clearly, as word processing problems often occur.
- Give short, one sentence explanations.
- Use short, simple sentences.
- Allow plenty of time for comprehension.
- Repeat instructions or sentences exactly the same way every time.
- Avoid insistence, try again later.
- Avoid confrontations:
  - Agree with them or distract them with a different subject or activity.
  - Accept blame (even if it's not the reality)
  - Respond to feelings rather than words.
  - Leave the room, if necessary
- Communicate in a conversational way rather than asking questions, which can make them feel tired or intimidated.
- Avoid 'reminders', as they remind them that they are becoming more disabled.

Basic Communication Don'ts for someone with dementia:
- Don't take it personally.
- Don't talk to the individual as a child, be patient and show respect.
- Don't dismiss their feelings, attempt to address the feelings directly.
- Don't correct, contradict, or insist on facts.
- Don't blame the person.
- Don't reason.
- Don't argue.
- Don't correct them, if possible.
- Don't confront.
- Don't rush or overwhelm them.
- Don't remind them they forget.
- Don't question recent memory.
- Don't ask if they remember something.
- Don't bring up a topic that may upset them.
- Don't assume they can't understand something.
- Don't speak down to them, this may frustrate them causing anger, anxiety or withdrawal.
- Don't take it personally, best repeated, over and over again.
- Above all, don't isolate them.

Finally, avoid the words and questions that can trigger anger or anxiety in a person with dementia, for example:
- 'Remember when...?' ...
- 'I've just told you that' ...
- 'Your brother died 10 years ago' ...
- 'What did you do this morning?' ...
- 'Do you recognize me?'

The following links provide more information on this topic.

https://www.alzheimers.org.uk/blog/language-dementia-what-not-to-say

https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/how-to-communicate-dementia#:~:text=Communicate%20clearly%20and%20calmly.,feel%20quite%20tiring%20or%20intimidating

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Confessions of a Caregiver:

Guest editor Debra Perina interviewed a nurse she worked with who is now primary caregiver for her husband who has dementia. She spoke candidly but wished to remain anonymous, so we will call her Dee (short for Demeter).

One fateful day 6 years ago, Dee's husband, Lethe (Lee), a neurologist, was diagnosed with progressive dementia. He was forced to give up his practice, and several months later progressed to the point that being home alone was unsafe. He was becoming increasingly confused, forgot things and then took to wandering.

Like many of us, they were empty nesters, with two grown sons living several states away with their own families. Trying to hire home sitters, to help when Dee worked, quickly failed, as Lee became increasingly paranoid and uncomfortable with strangers in the house.

Dee made a painful, but necessary decision, leaving her career as an RN in the Emergency Department. Thus, caring for him became her primary responsibility.

Although she wouldn't have it any other way, 6 years later she acknowledges this is the hardest thing she has ever experienced, and it has taken a great toll on them both. Dee has watched the man she loved become a shell of himself and someone she no longer recognizes.

She provided one example of the constant difficulties and adaptations made for this disease. Lee always loved reading, but as he progressed, he became a hoarder and would not let her throw or give away any books, magazines, or other written material. Even talking about doing it caused him great anxiety and anger outbursts.

Always a 'neat freak' it was extremely uncomfortable for Dee to live in collector conditions. His dementia had become so severe that friends told her to just unclutter when he was napping, since he wouldn't remember what he had and wouldn't miss anything. She couldn't make herself do that, both out of respect for him and concern that he actually would notice changes and become more anxious and depressed than he already was.

As he slowly lost touch with reality, Lee was aware he was doing so and became profoundly depressed, which, of course, only exacerbated symptom progression. Watching Lee's downward spiral also took a toll on Dee, although she expressed the desire to deny and hide it from friends and relatives.

"I'm supposed to be the strong one. I am a nurse and should be able to handle this as a professional caregiver, especially for someone I love".

The reality is, for us as medical professionals, that it's much harder to maintain a 'professional distance' when it involves our loved ones. Somehow feeling these most basic human emotions becomes a shortcoming or a luxury we think we shouldn't have.

Dee became profoundly depressed before finally admitting it to a few close friends who tried to validate the appropriateness of her feelings. Eventually, she sought treatment to help her cope.

However, she is still not comfortable sharing this information with others, outside of a select few, of which I am one (I worked with her in the ED for many years). Hence her concern that emergency physicians she previously worked with would read this. Since she wished to keep their struggles private, she will remain anonymous.

If that decision seems misplaced to you, consider this; her constant companion is guilt. She perpetually feels she could do more, should be doing a better job caring for Lee, and is not handling the responsibility as well as she should. She is reticent to have others help, except for her sons during their occasional visits.

Dee is embarrassed acknowledging that at times she feels impatient or angry when she can't go places or engage in activities she normally would enjoy, instead needing to be constantly present to provide for her husband. "Those are what a shallow, selfish person would feel. It's not his fault this disease claimed him".

Trying to persuade her that these emotions are human, what anyone in a similar position would feel, brings acknowledgement. However, this doesn't last long. "I should be able to handle this without such feelings!".

Guilt is a powerful humbler; as all of us in medicine have surely experienced when outcomes were not what we wanted. Self-questioning causes thoughts (although not valid) of not doing all we could have. The guilt is there no matter how unwarranted it might be.

My friend has chosen a hard road, but she quickly points out "this is the ultimate gift of love I can give him. He was a very proud person who'd want to keep things private."

An introvert herself, Dee does not feel comfortable asking (accepting) help or reaching out to resources that could help her adapt to (and gain) more perspective in being a primary caregiver.

As I write this, their journey is almost at an end. Lee has just been placed in hospice. One son has moved back into the house to help, as Dee can no longer manage to move him herself. Still, she wanted to share her thoughts since no doubt some of you are going through some variant of this.

To make the situation, 'careliving' with someone lost to dementia, the best it can be, also take care of yourself and your needs. After all your loved one would want you to do just that, and in the long run it will make you a better caregiver.

The demands of caregiving can limit one's ability to take care of oneself. Family caregivers of people with Alzheimer's and dementia are at greater risk for anxiety and depression, and overall have a poorer quality of life than caregivers of those with other conditions.

If you are, or know someone in a similar position, please take comfort in the knowledge that you, they, are not alone. Seek support and outside resources to help.

Resources for caregivers can be found at

https://www.cdc.gov/aging/caregiving/alzheimer.htm#:~:text=The%20demands%20of%20caregiving%20can,of%20people%20with%20other%20conditions.

And through the Family Caregivers Alliance

https://www.caregiver.org/resource/caregivers-guide-understanding-dementia-behaviors/

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Is It Rude To Say "Demented"?

Yes! Please remove the word 'demented' from your dementia vocabulary.

The American Geriatrics Society states, "…to say that a person has dementia is to say that she or he has a disease process that "undoes the mind," whereas to say that a person is "demented" is tantamount to saying that he or she no longer has a mind."

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In Case You Missed This:

In his JAMA, August 13, 2024, *A Piece of My Mind*, Dr. Joel Yager has summed up his family's methods for remaining relevant after 80 when "The (usually) more desirable path of outliving and "outhealthing" your compadres requires that you witness and accompany others who are close to you as they decline, suffer, fade, and die." It is a must read for those of you "…destined to experience loss, some degrees of grief, and the contraction of your previous social circle." After all, as he concludes, "Someone Has to be Around to Put Out the Lights."

https://jamanetwork.com/journals/jama/fullarticle/2821246

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From the Editor: A Clock Diary

Sometime after my husband began his 15 yearlong EBV (waxing and waning) dementia, we began drawing clock-faces. Every six months, I had him draw a clock face with the hands at a specified time, ten of two.

Typical of very intelligent individuals, he hid his early dementia well, even from me. To family, he grew quieter and withdrew from favorite pastimes like boating and reading to spend hours watching TV. To friends sharing common interests, he could still hold his own discussing history, politics, and other beloved topics of the past. To strangers, he appeared to be just a quiet, affable man. Initially, he had normal days and quieter days. Slowly, the quiet ones became more frequent.

But the clock did not lie. Over time, his clocks became more distorted. To me, the worst symptom was that he did not seem to notice the distortions.

I misplaced those early clocks during our last move. So, I got a small notebook and had Kork draw his clock on the left-hand page. Each time, after he finished drawing, concerned about my mentation, I drew a clock on the right-hand page. I continue to draw my clocks alone now.

The clock-drawing test (CDT) is a simple tool to check for dementia, but not it's etiology or type. It measures attention, visual memory, and motor skills. When directed by others, it assesses hearing comprehension. Reading face-based clocks requires interpretation of the hand placement and the time they are meant to represent, an ability lost by those with dementia. (I fear the future digital- generations will lack the background to use this simple test.)

My one big regret is my failure to start making a clock notebook when Kork first admitted he could not find his way home from the grocery store. If I had it to do over, in addition to the date, I would have listed his symptoms, diagnostics, managements, and my observations under his clock. Perhaps I would have put my thoughts about our changing life under my rendition of the clock. I now wish we had created a clock diary to chronical our long good-bye.

The linked article below explores the aims of the clock-drawing test, how it is done, and what the scores mean. It also discusses some of the benefits and drawbacks of testing:

https://www.verywellhealth.com/the-clock-drawing-test-98619

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Non-Verbal Dementia Communication

Those with dementia read and interpret body language. Sudden movements, harsh tones of voice, and tense facial expressions can upset or distress them, even if the accompanying words are not upsetting. It is important that body language and facial expression match what is being said, even if this feels forced at times. For example, be sure to smile when talking about pleasant memories.

Physical contact communicates interest and provides reassurance, so, when appropriate, hold the person's hand, put your arm around them, or hug them. However, it is also imperative to respect their personal space, so sit or stand at to be at their eye level. Sitting too close or standing over them to communicate can make them feel intimidated.

It is equally important to recognize what an individual with dementia is communicating through their body language. Respond to what you see, for instance by keeping them engaged if they appear distracted or bored.

Encourage them if they benefit from drawing or singing to express themselves. Provide visual prompts, such as cue cards, picture books of meals, and apps to help them communicate what they want to eat and also stimulate their appetite.

https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/non-verbal-communication-and-dementia#content-start
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Catch ya later, Grandpa…

By Chelsea Guffogg

My husband (Jim) and I moved in with my grandparents (accidentally) during the last year of his life.

We were contract educators, exploring America and going to my grandparents' home between terms to stay connected. It was during these times together that I really noticed a decline in my grandpa's cognitive ability.

During our visits, in the last two years of his life, as his dementia worsened and function declined, my grandmother (Mimi) would make wide eyes at me if she noticed he was a bit slower than normal or was behaving in a strange way; forgetting where a utensil was or neglecting to pick the larger pieces of eggshell out of the scrambled mix before dumping it into the pan when making breakfast.

He developed a significant tremor in his left arm, and often I would find him mouth open and drooling; onto his glasses mind you. We joked that the glasses caught crumbs as snacks for later. We never mentioned the drool.

Over the years, I found comfort in my grandpa's wisdom (sometimes unsolicited but always appreciated). So, when my husband decided to go back to school, what better way to figure out our future than by visiting my grandparents. As it turned out, we were lucky to have this time together.

My husband enrolled in online courses, and I worked remotely, so we extended our fall visit through the holidays into 2023.

Grandpa was still driving, and, in all honesty, I would say a prayer anytime I got in the car with him. His tremor made me the most nervous, along with the trouble he had turning to look over his shoulder when he wanted to merge.

I remember one day we drove to get the mail. I was less nervous, due to the 'speedy' 10 mph he drove on his ¼ mile long driveway. We pulled up to the mailbox positioned on the driver side, but he misjudged the space, so the wing mirror started to scrape. Most drivers would have reversed to reposition, but he just kept accelerating, ultimately scraping the car along the mailbox. I said nothing.

When we got back to the house, I found my grandmother and promptly informed her. We shared a look of concern that heralded an upcoming shift in driving patterns and habits. I heard her bring it up to him later that evening. He didn't have much to say. I think silence was his way of acknowledging that he knew he was starting to lose his judgement.

Thus, we transitioned driving from him to me. To ensure he still felt in control, I would offer to drive him, allowing him the opportunity to say "no"; but he never did. From that point forward, we found a balance, jesting to break potentially awkward moments, as I never wanted to compromise his dignity.

When Mimi's hip replacement surgery was scheduled for January, we decided to prolong our visit, so I could assist her during recovery and provide transportation to PT.

Towards the end of that six weeks, it was decided my grandpa would benefit from twice a week dementia therapies, even though these "experimental" treatments were an hour and a half away. "I'm on it!" I volunteered. And so, we extended our stay 8 more weeks.

Grandpa taught me to drive on a rural farm road when I was 12, so I appreciated these new journeys together, chatting, developing inside jokes, and creating memories for me to cherish today.

We made other accommodations accordingly. For instance, when he started inadvertently leaving the stove turned on, my grandmother made the switch to an induction stove so there was no possible chance of immediate fire.

One cherished memory from childhood was my grandfather making scrambled eggs. Breakfast was always his job.

“Get out of my kitchen” and “nope” were his consistent response to offers of cooking help. However, when we moved in, he slowly started to step away from that duty.

Drooling, tremor, and shuffling were ever present as my grandfather’s dementia progressed. My grandmother would signal to him, when she found him miles away with his mouth open, “Ben you’re drooling…”. She would find the nearest cloth and for him to wipe up. That was always my cue to look away, wanting to ensure he knew I still respected him.

Protectiveness became second nature. There were always aspects of my grandfather’s dementia that I never wanted to point out. I really wanted to do everything within my power to preserve his dignity and make him feel like he was in control -not in control of me, but in control of himself.

The hardest thing for me was figuring out how to communicate safety issues. Early on in our living together, in anticipation of anger or resentment from him, I felt hesitant to recommend what he should do. Suggesting he step aside or just get the door while I unloaded the car, for example, was met with resistance at first. I must give him credit, however, as he progressed, he never really put up a hard fight when I stated how we were going to do things.

I recall the turning point, when unloading groceries one day, he misjudged his ability and took a hard fall. I had to make sure not to put too much blame on myself. He was a grown man, once capable of anything.

As time passed, it was obvious he knew he was declining and now he needed me to be stern on safety issues. Nevertheless, even as an ‘adult’ grandchild, this role reversal felt very strange to me.

When I noticed changes in his behavior, my go-to move was to find my grandmother alone, or to ask her (using ‘shifty’ eyes) to step out of the room so I could explain to her what I was seeing. She was left to take care of whatever I had seen.

Mimi said the new therapy helped his tremor; Grandpa claimed, “It didn’t do shit,” with the occasional “well, maybe this is working.” I defer to the medical professionals. From my perspective, my grandfather had better days than others.

In April, Jim, finishing school, was interviewing for his “entry-level dream job.” Grandpa’s therapies were ending. (Funny, I don’t remember the last time being “the last time.”) I was running errands, my grandmother was out, and Jim was the only one home. I looked at my phone and had many missed calls from him – instantaneous concern.

My grandfather was starting to lose control of his bowels. He had always had a “bad gut,” and he would say that whenever I asked him over the years if he wanted to travel anywhere in particular. “I don’t travel anymore, Chels” he would say. I suspect was because he started to feel like he didn’t have control over the situation.

These moments of incontinence became more frequent. Jim had been an in-home-care professional at one point, so it never bothered him. But we both faced the challenge, in these moments, of how to preserve his dignity, especially when my grandmother was out.

May arrived. With brain therapy completed, Mimi mobile, and Jim remotely employed, we left to visit his family in England. Upon our return, we moved into our first “permanent” home (apartment) in six years. So, we officially, (accidentally) “moved out.”

I planned to find work in our new town but put it off for the summer to travel back and forth, a seven hour drive, to my grandparent’s.

In early July, we got the call. Grandpa had cancer. I spent my 30th birthday dinner with my grandparents and will forever hold that memory dear.

More short visits and I was back home for September to work and ensure my husband knew I was still “committed” to him.

My mother, staying with my grandparents and working remotely, called. I knew I needed to grab my ever-ready 'go-bag' and hop in the car. I drove in silence, alternating between admiring the Blue Ridge Mountains and trying to accept that this could be THE last time.

Grandpa was bedridden, unable to sit up for the last week. As I walked in that September evening, I could hear Mimi making her way back and forth from the bedroom to the bathroom, talking with my grandfather. Eventually she made her way down the hall, looking tired and sad.

I knew what Mimi-in-pain was like, having been her companion throughout her hip replacement, but this was a different kind of pain. She could barely keep her words together. Both my mother and grandmother are physicians and seemed to have a sixth sense about my grandpa's current condition.

I hugged her. We wept. There wasn't a dry eye. She suggested I have my dinner in the bedroom to "keep grandpa company."

I got my soup and sat on a stool at the end of his bed. Talk was brief. He was staring at the ceiling but seemed lucid.

In the past, conversation flowed, but this time was different. We were always comfortable with silence; simply being in each other's company was enough. I knew he would ask questions if he wanted to know something, and I would ask him about his past if I wanted to hear a story.

I was used to hearing the same stories throughout the years, especially during the last two. I don't know if he forgot what he had told me, if he just really enjoyed telling them, or if a story was his way of connecting. Regardless, I was all ears, trying to pretend like I didn't know what was going to happen next.

I'll spare you the inappropriate limericks, but there was one story about a captain and his first mate that sums up my experience with my grandfather's story telling throughout his dementia:

"It was a dark and stormy night, and the First Mate said to the Captain "tell me a story" and this is the story the Captain told… "it was a dark and stormy night, and the First Mate said to the captain, tell me a story, and this is the story the Captain told…"

Well, you get the picture. This is a perfect description of how it felt to be on the other end of his dementia.

I never minded it, but there was not a new story for years before he died. I always enjoyed egging him on; it kept him engaged and aided his memory in the last few months of his life. It was a tether to the past and to his identity as a tugboat captain - and that was important to maintain.

This visit, having dinner in his bedroom, was different. It felt more strained. The man I loved and looked up to was physically leaving. So, I asked about pictures in the room or chose personal topics, like my husband's new job, and we talked intermittently.

After dinner, I found my way onto my grandmother's side of the bed, cozying up and asking him questions, even the hard ones like, "are you ready to die?"

"Yes."

"Are you afraid to die?"

"No, but I am scared of what I will miss." That lingers still.

That was the last conversation I had with him.

He was lucid. He was present. He was Grandpa. My most fond memories of him entail our long talks throughout the years; from solving world problems to discussing life lessons. To have an ultimate moment like this, where we were able to connect on such a deep level, soaking in his perspective and wisdom, created a magical, full circle moment.

He knew who I was at the end - what a gift.

Accidentally moving in with my grandparents was a most serendipitous event.

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The Phenomenon of Terminal Lucidity

Dementia is often described as "the long goodbye." Although the person is still alive, dementia slowly and irreversibly erodes their memories and what made them who they were. It eventually claims the essence of the individual - their ability to communicate, complete basic tasks like feeding themselves, identifying where they are, and recognizing family members. Loved ones watch this process slowly chip away the person they love until they become unrecognizable. The grief of bereavement begins with acknowledge of dementia and often lasts years until death.

Since the 19th century, caregivers and health workers have described individuals with dementia who suddenly became lucid, engaged in meaningful conversation, shared memories that were assumed lost forever, and even requested meals. Up to 43% of people who experience this brief lucidity die within 24 hours, and 84% die within a week. Hence the moniker 'terminal' lucidity.

No one knows exactly why this happens. Moments of lucidity do not necessarily indicate imminent death. In fact, many with advanced dementia have shown brief glimmers of their old selves up to six months before death.

Lucidity has also been reported in other conditions, particularly those that affect the brain or thinking skills, such as meningitis, schizophrenia, brain tumors, and those who have sustained a brain injury.

Scientists struggle to explain why terminal lucidity happens. Some episodes occur in the presence of loved ones, while many episodes have no distinct trigger. It's been speculated that changes in brain activity before death may cause terminal lucidity. But this doesn't explain why people suddenly recover lost abilities.

Terminal lucidity is very difficult to study. Not everyone with advanced dementia will experience lucid episodes before death. They are unpredictable and typically occur without a particular trigger.

While terminal lucidity can be a joyous time for those who witness it, scientists have challenges in conducting research at or near the event. It's also difficult, at the time of the patient's death, to interview caregivers to ask about lucid moments.

Explanations for terminal lucidity seemingly extend beyond science. These moments of mental clarity may be a way for the dying person to say final goodbyes, gain closure before death, and reconnect one last time with family and friends. There is also a belief by some that terminal lucidity represents the person connecting with an afterlife.

Although the true explanation is not known, one thing is certain - those who experience it in loved ones or patients they are caring for find comfort, and even closure, in the event.

However, it's important to remember these lucid episodes are temporary and sadly do not represent a reversal of neurodegenerative disease.

People can have a variety of reactions to terminal lucidity in advanced dementia. While some experience it as being peaceful and bittersweet, others find it deeply confusing and upsetting. There may also be an urge to modify care plans and request previously unwanted lifesaving measures for the dying person.

Awareness of terminal lucidity can help loved ones understand it as part of the dying process, while acknowledging the person with dementia will not recover, and allow them to make the most of the time they share with the lucid person.

For those who witness it, terminal lucidity can be a final, precious opportunity to reconnect with the person who existed before dementia took hold and the "long goodbye" began.

More on this topic:

https://theconversation.com/terminal-lucidity-why-do-loved-ones-with-dementia-sometimes-come-back-before-death-202342

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