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OUR VIEW

Down the rabbit hole

Alzheimer's caregivers struggle with exhaustion, isolation

KATHY ANEY
Comment

Hello Alzheimer's.

About six years ago, my mother-in-law's neurologist gave her news that no one wants to hear — she had Alzheimer's disease. The heartbreaking diagnosis was a gut punch. We tried to imagine this outgoing, savvy woman just sliding away into oblivion — this mother of three, gourmet cook, singer, outdoorswoman, retired travel agent and center of family life.

Joyce Johnson and Warren Aney met at age 14 at a church summer camp. The Stanfield girl and the Umatilla boy immediately connected.

"She was the second girl I kissed," said Warren, flashing back on his teenage self. "The first girl was a couple days before."

Their personalities meshed in interesting and lovely ways, he said, and they married at age 19. The couple raised a family in Portland that included several foster children. They took the kids on cross-country ski trips and camping adventures in their Volkswagen minivan. They were a team.

After 55 years, the relationship shifted. Warren, a retired regional manager for Oregon Fish & Wildlife, spends his days taking care of Joyce. She is wheelchair-bound, so he shuttles her between different spots in the house — the bed, the toilet, the dining room table and the easy chair in the family room. He feeds her and makes sure she gets her medications. He takes her to church and parks her in the front row because "I want her in the center of things." He is constantly tired, but committed.

"The alternative is not to have her here and that's worse — not to be with her," Warren said.

So he concentrates on each day, one at a time. He knows the ultimate trajectory down this rabbit hole, however, and says when the time is right for Joyce to move to a nursing facility, he will let her go. He refuses to dwell on that future.

"If you dwell on it, it could be depressing, but I don't have time to dwell on it," Warren said. "My obligation — my opportunity — is to take care of her as long as I can."

Warren and Joyce aren't alone in their daily struggle. As America ages, the number of people with Alzheimer's rises. According to Stephanie Barnhart-Herro, program director of Oregon Care Partners, there are 60,000 Oregonians with the disease.

"The population is aging really rapidly," she said. "By 2020, the number of Oregonians over the age of 65 will increase by 63 percent. The biggest known risk factor for Alzheimer's is age."

She said a diagnosis of Alzheimer's can feel like having your world pulled out from under you.

"They've been given this really scary diagnosis, but are not really told what to do," Barnhart-Herro said. "For caregivers, the stress is huge. That's the other side of this disease."

Caring for someone with Alzheimer's is a daily slog. There's no manual, though Oregon Care Partners offers online classes and trainings in various cities around the state.

"It's a 24-hour-a-day job and oftentimes caregivers don't have time to care for themselves," she said. "According to the Alzheimer's Association, it can last from two to 20 years. The way it progresses is different for everyone."

Elaine Eshbaugh writes about the disease in her blog, "Dementialand." The associate professor at Northern Iowa University is the Division Chair of Family Services and Gerontology and the daughter of my friend, Sue Dwyer. When Sue worked as activities director at a nursing home many years ago, young Elaine wandered among the residents.

"Some people are military brats," said Eshbaugh, speaking Thursday by phone. "I was a nursing home brat."

The little girl especially connected with residents who had dementia.

"They were in a different time and place," Eshbaugh said. "They were the best playmates ever."

Her unique blend of experience, education, research and counseling means Eshbaugh has plenty of road-tested advice for caregivers. To stay sane, she advises family caregivers to:

• Take care of yourself. "We have a culture of independence and a superhero mentality. Your health has to be as important as their health. This is a marathon, not a sprint."

• Pick your battles. She tells the story of a woman with Alzheimer's who spent three hours a day loading the dishwasher with clean dishes, then unloading and repeating. "It drove her family crazy, but it made her feel useful. In the end, they came to terms with it." Another person read the same chapter of a book over and over. Eshbaugh sees no problem with this behavior. "Sometimes we create problems when there aren't any problems."

• Learn that being totally honest is sometimes not the right thing. She told of a woman who repeatedly asked when her long-deceased mom would be coming home. Instead of setting her right, her caregiver learned to say, "She will be back soon." "We call this 'therapeutic fibbing' or stepping into their reality."

Eshbaugh also urges caregivers to do as Warren does and focus on the day. In addition, she advises caregivers to forget about people who aren't supportive, to accept help, forget feeling guilty and have a sense of humor.

"Figure out what makes you laugh and actively seek that out," she said. "And don't feel guilty for laughing."

Warren echoed Eshbaugh's advice to take care of yourself first. After injuring his back during a lift, he learned lift techniques and vowed not to take chances with his own health.

Joyce's short-term memory has faded, though she still has some long-term recollections. She stays quiet most of the time, but pipes up unexpectedly.

The other day, Warren toiled over a crossword puzzle. When he couldn't remember the name of "Lucy's husband," he asked Joyce.

"Desi," she said.

Warren has learned to celebrate those moments of connection. He smiled.

In a poem Joyce penned shortly after her diagnosis, she wrote "They say that eventually I won't recognize my sweetheart of 50-plus years. What a heartbreak ... Remember me as a compassionate, creative, giving soul who loves her life as it is, but not as it will become. Maybe this is just a bad dream. Please I'm ready to wake up now."

Warren once asked himself whether he would have married his high school sweetheart had he known she would get Alzheimer's and require years of caregiving. The answer, he said, came without hesitation.

"Our life together has been greatly enriched with wonderful children and grandchildren, with shared adventures and experiences, with jointly developed social and religious linkups, with similar but complementary appreciation and celebration of arts and nature," he said. "Given this rich and rewarding relationship over so many years and the realization that Joyce is still partly able to maintain and appreciate this relationship, I would not have done it differently."

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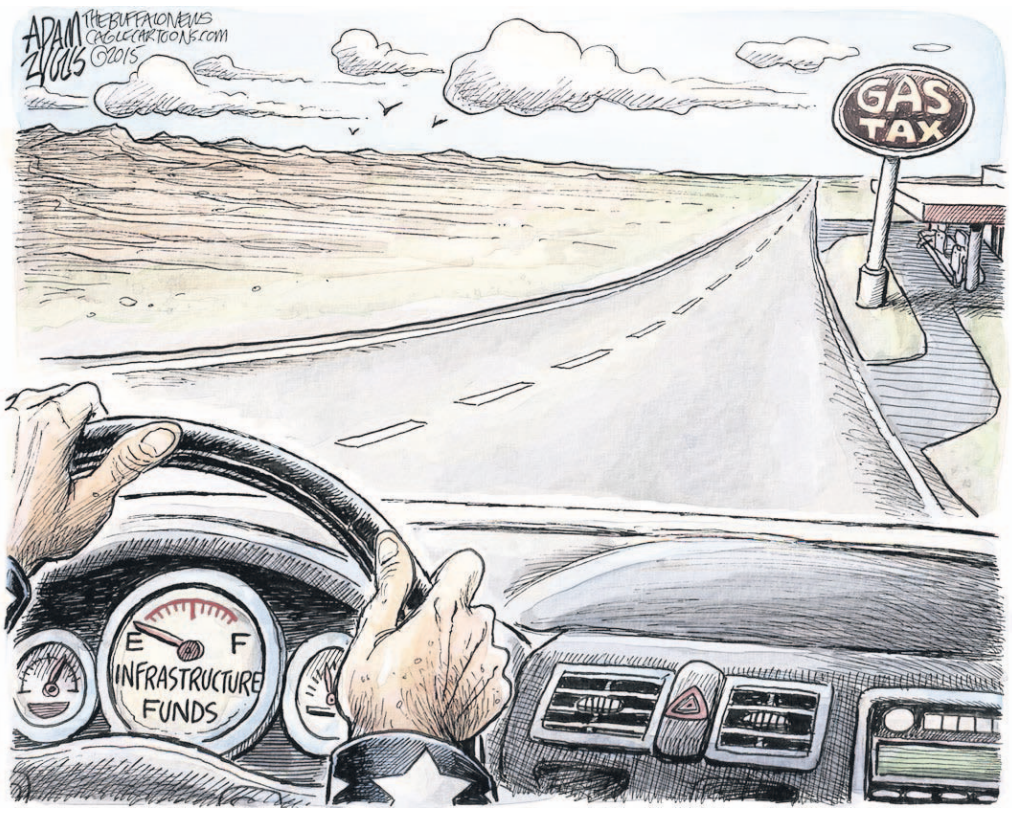
Kathy Aney is reporter for the East Oregonian.



OTHER VIEWS

Listening to Ta-Nehisi Coates while white

DAVID BROOKS
Comment

Dear Ta-Nehisi Coates,

The last year has been an education for white people. There has been a depth, power and richness to the African-American conversation about Ferguson, Baltimore, Charleston and the other killings that has been humbling and instructive.

Your new book, "Between the World and Me," is a great and searing contribution to this public education. It is a mind-altering account of the black male experience. Every conscientious American should read it.

There is a pervasive physicality to your memoir — the elemental vulnerability of living in a black body in America. Outside African-American nightclubs, you write, "black people controlled nothing, least of all the fate of their bodies, which could be commandeered by the police; which could be erased by the guns, which were so profligate; which could be raped, beaten, jailed."

Written as a letter to your son, you talk about the effects of pervasive fear. "When I was your age the only people I knew were black and all of them were powerfully, adamantly, dangerously afraid."

But the disturbing challenge of your book is your rejection of the American dream. My ancestors chose to come here. For them, America was the antidote to the crushing restrictiveness of European life, to the pogroms. For them, the American dream was an uplifting spiritual creed that offered dignity, the chance to rise.

Your ancestors came in chains. In your book the dream of the comfortable suburban life is a "fairy tale."

For you, slavery is the original American sin, from which there is no redemption. America is Egypt without the possibility of the Exodus. African-American men are caught in a crushing logic, determined by the past, from which there is no escape.

You write to your son, "Here is what I would like for you to know: In America, it is traditional to destroy the black body — it is heritage." The innocent world of the dream is actually built on the broken bodies of those kept down below.

If there were no black bodies to oppress, the affluent dreamers "would have to determine how to build their suburbs on something other than human bones, how to angle their jails toward something other than a human stockyard, how to erect a democracy independent of cannibalism."

Your definition of "white" is complicated. But you write "'White America' is a syndicate arrayed to protect its exclusive power to dominate and control our bodies. Sometimes this power is direct (lynching), and sometimes it is insidious (redlining)." In what is bound to be the most quoted passage from the book, you write that you watched the smoldering towers of 9/11 with a cold heart. At the time you felt the police and firefighters who died "were menaces of nature; they were the fire, the comet, the storm, which could — with no justification — shatter my body."

You obviously do not mean that literally today (sometimes in your phrasing you seem determined to be misunderstood). You are illustrating the perspective born of the rage "that burned in me then, animates me now, and will likely leave me on fire for the rest of my days."

> I think you distort American history. This country, like each person in it, is a mixture of glory and shame. There's a Lincoln for every Jefferson Davis.

I read this all like a slap and a revelation. I suppose the first obligation is to sit with it, to make sure the testimony is respected and sinks in. But I have to ask, Am I displaying my privilege if I disagree? Is my job just to respect your experience and accept your conclusions? Does a white person have standing to respond?

If I do have standing, I find the causation between the legacy of lynching and some guy's decision to commit a crime inadequate to the complexity of most individual choices.

I think you distort American history. This country, like each person in it, is a mixture of glory and shame. There's a Lincoln for every Jefferson Davis and a Harlem Children's Zone for every KKK — and usually vastly more than one. Violence is embedded in America, but it is not close to the totality of America.

In your anger at the tone of innocence some people adopt to describe the American dream, you reject the dream itself as flimflam. But a dream sullied is not a lie. The American dream of equal opportunity, social mobility and ever more perfect democracy cherishes the future more than the past. It abandons old wrongs and transcends old sins for the sake of a better tomorrow.

This dream is a secular faith that has unified people across every known divide. It has unleashed ennobling energies and mobilized heroic social reform movements. By dissolving the dream under the acid of an excessive realism, you trap generations in the past and destroy the guiding star that points to a better future.

Maybe you will find my reactions irksome. Maybe the right white response is just silence for a change. In any case, you've filled my ears unforgettably.

■

David Brooks became a New York Times Op-Ed columnist in September 2003.

YOUR VIEWS

City can't track committees, can't track our money either

When is a committee not a committee? I thought since April that I was attending the Capitol Improvement Committee. At the July 7 council meeting Mayor Houk informed me that I had been attending Capitol Investment Advisory Committee.

If you are confused, so is the city staff. The next morning I asked the city attorney when this committee was formed. They did a computer search but could only find a reference to the committee last November, not when it was formed. That afternoon I asked the city staff if they could find who was on this so-called committee. They could not find any record of who was on this committee.

If this is not an official committee, how can it recommend anything to the city council? But this happened at the July 7 meeting under the names of Bob Paterson and Robb Corbett.

Can we trust the city with all this new tax money if they cannot keep track of a phantom committee?

At one time Pendleton was the largest city between Portland and Salt Lake City. Those times are long gone. We have to compete for jobs, business and industry with cities that do a better job of managing their money. It already costs more to live in Pendleton than surrounding cities. Can we afford to add to this burden? The city collects over $2.5 million from us in franchise fees, this is for use of the public rights of way (roads). I think at least half of this amount should be used for street repair. What do you think?

Finally, we have spent a few hundred thousand dollars on Portland consultants for things that never happened. How about spending a little money on a consultant from Eastern Oregon on how to cut city spending?

Rex J. Morehouse
Pendleton

LETTERS POLICY

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