

Policy Forum

From the bedside: “A terrified witness to the future.” A baby boom generation wake-up call

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I am a former TV journalist, not a scientist, nor a neurologist or a gerontologist. Why do my personal observations warrant a place in a scientific journal? Let's just say I have put in more than a decade of “on the job training” and “real time testing” of the latest therapies designed to slow the progression of a disease that will ravage the baby boom generation.

Alzheimer's disease (AD) is a pending epidemic greater and deadlier than a flu pandemic. No one survives its onslaught. The blessing of our greater longevity turns perverse and clouded by the growing risk of Alzheimer's disease. Studies show that those who get the disease have the bio marker in them between 10 to 20 years before exhibiting any symptoms. We are ticking time bombs without even knowing it. How ironic that the generation that wouldn't trust anyone over age 30 and still embraces youth is now succumbing to a scourge linked to age.

While you are in the laboratories and clinics searching for new AD therapies and protocols, I am at the bedside trying to manage symptoms and grotesque behaviors, pained by the cruel realities of a disease for which there is currently no cure.

At night I slip between the bed covers, careful not to disturb the stranger lying there. His eyes are closed, but I take no chances. He is aware of me but does not know me. I turn into him and begin to breathe in a slow steady rhythm that mesmerizes him into a temporary slumber. I have learned to succeed where drugs have failed. The reprieve will be short and the night long. Soon he will wake screaming and flailing his arms as if fighting off demons. The terror of his world is my world: I am his captive and victim to a once brilliant, but now demented mind. Any challenge is self-defeating and useless; I play to his realities in order to survive. Exhausted, I drift off only to re-awaken and find

myself lying by his side in a pool of urine. It is both an insult to my sensibilities and a signal that tonight we have passed into an Amber alert of endless terror.

That's a snapshot of my night shift. Each morning, I re-introduce myself to my husband of 25 years. His eyes are blank, and mine fill with tears. In effect, I have been “slow dancing with a stranger” ever since my physician–husband was diagnosed 11 years ago at age 58. A hematologist/oncologist, he devoted his life's work to unraveling rare blood diseases while unknowingly fated by a genetic predisposition to another incurable disease. Today he is late-stage dementia, 24/7 care, and still at home.

I am the “ultimate desperate housewife” and part of the statistic that assesses the economic value of informal care giving at \$257 billion dollars annually. As “informal” caregivers, we have juggled work and care giving, abandoned careers for part-time employment, been forced into early retirement, and jeopardized our own retirement futures. None of us think of ourselves as martyrs or selfless. We are just doing what needs to be done for a loved one. But what happens to them if something happens to us?

Every caregiver's story is unique, yet somewhat the same. But when the onset is early, it is like being witness to a future that will ravage our baby boom generation. I am terrified for all of us, and time is running out.

We need to fast forward to the future to fully comprehend why our generation (1946 through 1964) that begins turning 60 this year, must mobilize now and drive research toward a cure for AD in our lifetime.

If 60 is the new 40, be forewarned that there is no cosmetic fix for an intellect robbed or a mind unraveled. None of us would consider living with Alzheimer's as a life worth living.

The hospital doors locked behind us. My constant shadow would have to remain sequestered in a special ward for further evaluation. Just two weeks earlier, a top neurologist had misdiagnosed my doc with a clean bill of health. At a medical conference in Europe the next week, he got a

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fever that multiplied the same symptoms I had documented for the neurologist 10-fold. Confused and delirious, he was shipped home to me, captured at customs, and checked into the hospital under an assumed name to protect his privacy. It was there the nightmare unfolded. A powerful sedative given by a night nurse as a prn (PRN), turned an anxious man into a zombie. All the trial and error protocols with anti-psychotics made him more aggressive. He never sat down, paced the ward, was fed walking, and all personal care was a confrontation. It took four male nurses to hold him down for a blood draw. In the front lines of his daily care, I was ignored and dismissed by staff physicians when I reported a blood clot in his leg. "We're in charge of his care and you are his wife." Two and a half months later, the doctor's final diagnosis read: "Early-onset Alzheimer's with a behavior disorder. Your husband is too dangerous to come home."

Alzheimer's is cruel. It robs you and your family of the present and the future. More devastating than "lost memories," Alzheimer's slowly steals one's intellect, one's ability to communicate, one's independence, and one's dignity.

We need to revisit how we talk about AD in mainstream media. It may be nostalgia to romanticize the plight of those suffering with AD with a tagline "Because memories should last a lifetime," but it is defeating when trying to compete for federal research dollars. It ignores the true face of the disease and belies the hidden horror faced by victims and their families. Most importantly, it undermines a call to action by the body politics—now further distracted with a "Maintain your Brain Campaign" that suggests an adult can control with diet, exercise, crossword puzzles, and dancing whether they end up with AD.

This prevention campaign plays into the "control your own destiny" mentality of botoxed baby boomers.

The truth is that my husband "maintained his brain" – over 200 published research papers, fluent in 3 languages, and crossword puzzles in ink. A long-distance runner—he was physically fit, and it just didn't matter.

What an insult to those lost to the disease and how self-defeating to a cause. Even baby boom politicians when lobbied say we shouldn't be surprised that AD research budgets don't match those of other diseases that impact far fewer people. Where is the passion and political support? What is the rallying cry?

Currently 4.5 million Americans—our parents, grandparents, brothers, sisters, and spouses—are living with AD. This number has more than doubled since 1980. In our lifetime, if unchecked, the ranks of those living with Alzheimer's will grow to 16 million, more than the combined populations of Tokyo and Chicago. Imagine one of those cities filled with half of its residents totally dependent on others, unable to remember their identities, easy prey to abuse and neglect, hidden away in designer warehouses, society bankrupt of a generation's intellectual capital, and robbed of humanity.

Alzheimer's abuses and tests a caregiver's endurance. Together we are trapped in a "long goodbye" that could last for years because he is young and relatively healthy. I apply to have my husband participate in clinical trials so vital to basic research on the disease, but we are not even wanted there.

My husband is 69. The average lifespan from diagnosis to death is eight years—the range is from three to 20. We're into year 11; the first five years I managed alone until the doctors became concerned about my health and physical safety.

The latest AD therapies work only to delay onset of the symptoms long enough so that a person dies of something else. Most Alzheimer's patients die from secondary infections in nursing facilities. At home, my husband will live a long time. He'll outlast our finances. Medicare pays for acute, not long-term chronic disease. No financial planning ever projected the cost or the pain.

Thirty years ago, AD was regarded as a hopelessly untreatable condition. Today, the field is on the brink of major breakthroughs that may lead to more effective treatments and, ultimately, to prevention. Intensive studies are underway on multiple fronts, from basic science to genetics to drug therapy to care giving.

So where is the call to action, and who leads the charge? Unlike human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) activism or that of breast cancer, Alzheimer's victims are behind closed doors, and their caregivers are too worn out to protest.

The rally for research and a cure for Alzheimer's needs to be waged by a self-interested population that has everything to lose if a cure is not found in their lifetime. It's about us.

We are a transformational generation. We are 75 million strong and a majority of the body politic—a force to be reckoned with if we are focused in our attack to cure AD, which is now preying on our parent's generation as we hopelessly watch and choose between agonizing alternatives. Let's use our political capital on a challenge that will save us as well as generations to come. This call and response to action is something we know how to do. It's part of our emotional DNA imprinted by our campus protests of the 1960s.

So I will sound this call to action here: ARREST AD! (Activate Research, Reinforce Education, and Support Treatment for Alzheimer's Disease).

Among our first priorities:

- We must prioritize the work already being done to develop meaningful therapies for Alzheimer's. A widespread complacency exists today driven by the misperception that there is only vague hope in the grey distance. This is simply untrue, as years of research on how to stop the effects of β -amyloid, for instance, are very near producing

a viable drug that could halt or reverse the disease's erosion of the brain. But the process for reviewing such research and developing such drugs is slower than it has ever been before, and much less urgent than it is for other life-threatening diseases like cancer.

One of the most important obstacles is a very low tolerance for risk of side effects from promising drugs on the part of the US Food and Drug Administration (FDA), which understandably seeks to protect patients. But everyone I know who knows Alzheimer's would argue that side effects are a risk we are willing to take when faced with the single, currently inescapable alternative.

- We must make AD part of the national political dialogue. Although we are not in competition with other diseases, we want our voice heard. We need to put the \$1 billion request for increased National Institutes of Health (NIH) funding in the proper perspective. Look at the findings of the 2004 Lewin Report on what delaying the onset and slowing progression of Alzheimer's disease would mean in terms of stretching federal health dollars. It would mean:
 - A \$51 billion savings a year to Medicare by 2015.
 - A \$10 billion savings in annual Medicaid spending on nursing home care at the state and federal level.

The President rightly mentioned HIV and AIDS in his State of the Union Address, but did not mention AD. Even though the President did bring up health care costs and the challenge posed by aging boomers, he failed to note that Medicare expenses related to AD are expected to increase from \$91 billion in 2005 to \$160 billion in 2010, possibly representing the last straw that breaks Medicare's back. NIH allocated \$656 million to Alzheimer research in 2005. Under the 2007 budget proposal submitted by President Bush, funding for Alzheimer research would decline to \$645 million. In fact, the FDA's strategic plan that details its top priorities mentions obesity, HIV and AIDS, cancer, and many other diseases but never once mentions Alzheimer's disease. Because Alzheimer's often silences its victims, we must speak for them.

- We must recognize the unbearable burden that Alzheimer's places on caregivers and the family. What we need to understand is that when a family member with Alzheimer's ends up in an institution, it is not because the spouse or family has not tried to take care of him or her. It is

because it has become too physically and emotionally difficult, the caregiver gets sick, children are at psychological risk, or it is just too dangerous to keep them at home. It is clear that families cannot do it alone.

These are just three areas of action—translating scientific breakthroughs into treatments, giving Alzheimer's a political voice, and supporting our caregivers. All of the above speak to the need for more money for research, a collaborative environment to develop better therapies and better diagnostic tools with the end game to find a cure—the sooner the better.

Our generation already has models to follow as we respond to these calls in the activism and advocacy associated with HIV and AIDS and breast cancer.

Battling prejudice and an unresponsive health care system, in a climate not unlike the ageism facing the AD community today, the first generation of AIDS patients made a dramatic difference—perhaps none as lasting as its imprint on the drug approval system. Rather than wait for data while patients got progressively sicker, regulators were pushed to use so-called surrogate markers to determine whether a drug boosted white blood count or temporarily put the disease in remission. Because it was presumed that these surrogate markers were strong predictors of efficacy, relying on them enabled AIDS drugs to get priority review without having to spend years determining which drug actually helped people live longer while others died.

What is different today than at the beginning of the epidemic is that people with HIV and AIDS have won respect and recognition. They have a seat at the table. Never again will a major drug announcement or policy decision in this field be made without taking the community into account. They are a model for effective advocacy.

Yet, we don't see protestors decrying AD or insisting on access to promising new drugs that have gotten bogged down in a regulatory system that does not see the urgency. We do not see a national political leader declaring war on Alzheimer's, or a community literally redirecting medical research, as activists did with AIDS.

Breast cancer activism, begun in the early 90s by women for women, has translated into a five-fold increase in federal funding for cancer research and a 15% drop (1% per year since '91) in cancer deaths. Early detection and better treatment play a role, but most significant are the new drug therapies that are less punishing and invasive than surgery or chemotherapy.

Statistically, women are also at increased risk for AD. We outlive men, and those who do not become victims themselves are likely to be the primary caregivers. And still, Alzheimer's has yet to be embraced by the women's health movement.

In the years since the explosion of the AIDS epidemic and the "war on cancer," much has changed, which is a

tribute to those movements. The affected communities came together to take on a common, lethal foe, complementing activism with alliances that mobilize dedicated scientists, policy experts, politicians, and patients. Protest marches have been turned into more gentle and sympathetic events, like breast cancer's "Race for the Cure," that mobilize wider support than ever before.

So what are the lessons to be learned here? Simply that, as in the past, a handful of voices raised in concert can be a "tipping point" and help turn the tide.

Where do we go from here? What are specific things we can do in response to the call to action? In the Alzheimer's community, some consensus is emerging about things that need to change. The Alzheimer's Association has made the world a different place for their efforts. Local chapters have made support possible for many caregivers and patients, especially when hope for a cure was so far off. Now, we all must focus on bringing treatments to patients.

Marching under the ARREST AD banner, we need to change the attitude at the FDA and make Alzheimer's disease a top priority. The agency needs to rethink the overly protective high bar set for drugs to treat Alzheimer's patients and those at clear risk for the disorder. While safety must remain paramount, patients and their family proxies need the freedom to choose therapies that have a reasonable chance of success. In effect, this is how regulators responded to the HIV and AIDS community 25 years ago. If there is a chance something will help, why shouldn't we have that chance—and the choice?

In desperation to manage my husband's behaviors and care for him at home, I went on the Internet to purchase a drug, used successfully in Europe for late-stage dementia over the last decade, prior to FDA approval here. When my source dried up, I went to France and bought the drug over the counter. Initially, my husband responded in a marginally improved way. The reprieve lasted 8 months with minimal side effects. We were buying time and I have no regrets.

In the same vein, developing new drugs can currently take a decade or longer. That is a long time to wait knowing there is little solace for patients and families. We need a complete rethinking of the timeline needed to develop and approve new drugs for AD befitting that this is a public health emergency equal to any priority facing the American public. If we need a vaccine against a potential pandemic flu epidemic, shouldn't we have a preventive that can halt amyloid plaque from clogging the brain?

The regulatory process and trends in funding research need to look at just how far Alzheimer's research has come in the past few years and how much real momentum it could wield, if only encouraged. In addition to better understanding how β -amyloid plaque may cause the disease, and how a vaccine could target these protein components to halt the brain destruction, advances are also on track for more accurate testing and diagnosis. We are learning more about

how other conditions, like depression, that often occur with Alzheimer's, may represent clues on the cause and treatments. These are just as concrete as any breakthrough research ever was in cancer and AIDS. They should be supported just as emphatically.

Another ARREST AD commitment must be the passage of the Alzheimer's Research, Prevention, and Care Act which has languished in Congress for three years. This bill has garnished bipartisan cosponsorship from active members on the Congressional Alzheimer's Task Force. But the task force can't do it alone—they need stronger support from AD advocates in their districts as well as the attention of the President. Isn't it time, as the bill would require, that NIH make Alzheimer's research a priority and back up the promise with a billion dollar budget? This imperative must be brought home to drug companies so that their scientists can be empowered to develop vaccines and treatments that are currently on the bench or in the pipeline. Products for sexual dysfunction and baldness may be life enhancing but are not life saving, and so-called lifestyle drugs are certainly not a priority.

The brain is the remaining "black box" of science. It is time for the medical and research communities, as politicized as any branch of government, to focus on fast-track translational research that cuts across brain diseases in a more disciplined way than merely a subterfuge to short-change each other's lifework.

If this is too harsh, I don't mean it that way for I am married to a once-passionate physician who lived and breathed his research to the detriment of balance in his life. NIH colleagues no longer call or come to visit us: it is simply too hard for even seasoned scientists to see their mentor or cohort mindless to AD.

My personal Cliff notes on Alzheimer's are meant to trigger alarms. For our generation of Baby Boomers, 75 million strong, this kind of outcome for our lives is unacceptable, and we need to fight it.

Think of the challenge for researchers as unraveling the DaVinci code of the mind. If advances in genetics and imaging give scientists the tools they need to find risk factors for Alzheimer's rather than waiting for symptoms to appear, what are we waiting for?

Our baby boom generation with its unique history of confrontation and collaboration is facing a choice: take on Alzheimer's, a killer of minds and the enemy that terrorizes our lives, or wait passively for what we know will be tremendous hardships for our families and a long tortured decline into mental oblivion for millions of us.

Once again the terror of Alzheimer's revisits me with another face. I let myself into the apartment with a fearful anticipation of every adult child that has respected an elderly parent's wishes too long. I have aided and abetted the illusions of independence of my proud 85-year-old teacher-mother who wants to live alone. She prides herself on

still having a brain and shows off her talent for pithy rebuttal to her live in companions CNN and C-Span. A meticulous and organized woman, I search for telltale signs of disarray as a mirror to the creep of confusion overriding reality. As her only remaining child, I am now a target for the rage of forgetting. Misplaced items are perceived stolen even when retrieved. The refrigerator is a potential Pandora's Box of poison—checked daily, edited, and refreshed for the lady who once loved to cook and now forgets to eat. The actress in her puts on a show for the doctors even though she is out of sync with the time or the place. My mother has warned that she has hidden away pills to make certain she leaves us with her mind intact. How can I tell my mother she

is “losing it” too? Denial will rescue her as it did my husband because the disease first overrides the area of the brain that wipes out cognition of reality. But it will be a painful and protracted nightmare I share with millions of others as we watch our parents succumb to a disease that is our fate if a cure for Alzheimer's is not found.

None of us here wants to be a burden to our children. It's not too late for our generation. We must "Activate Research, Reinforce Education, and Support Treatment for Alzheimer's Disease" as part of our response. Unless we are ready as a generation to become a silenced and wasted footnote in history, we must make ARREST AD our mantra and refuse to go down without a fight.