

The Reality of Alzheimer’s Disease: The Untold Truth

by Dana Larsen

Alzheimer’s disease is an uncomfortable topic that has been kept pretty quiet in mainstream culture. But with the aging baby boomer population reaching 65+ in record numbers, new information, conversations and research is being done to help find a cure for this debilitating disease. And Meryl Comer, seasoned broadcast journalist and President of the [Geoffrey Beene Foundation Alzheimer’s Initiative](#), provides powerful insight as an Alzheimer’s caregiver and support advocate.

Even as I was setting up an interview with Ms. Comer I was impressed by her choice of words and knowledge relating to [Alzheimer’s disease](#): “Caring for someone with Alzheimer’s is not custodial care; it’s very intense, intimate, intimidating and 24/7.”

These powerful words resonated with me as my grandmother has Alzheimer’s and I’ve witnessed what the disease does to someone first-hand. While I’ve been researching and writing about Alzheimer’s for months, I’ve noticed that the human element of the disease somehow gets lost; the actual suffering involved with what it does to loved ones becomes overshadowed by a medical label. However, through a granddaughter’s eyes, I no longer see my grandmother, but a shell of what she once was — almost as if an alien had taken over her body. While this sounds awful, it describes what the disease has done. My grandmother has become a stranger. Meryl found a way to speak to this sadness and offered even more — a sage Alzheimer’s understanding and perspective.

Alzheimer’s Awareness: Recognizing When Something is “Off”



Meryl Comer in panel discussion of “Rock Stars of Science,” hosted by Geoffrey Beene Foundation & Research America. Photo courtesy of Paul Morigi/Getty Images North America.

Meryl and her husband, Harvey Galnick, once lived in the Washington swirl of media and medicine— she as the anchor for the television debate show, *It’s Your Business*, and he as a doctor, heading up hematology and oncology research at the National Institutes of Health. Their ‘picture-perfect’ life was in for a makeover not of their choosing,

however, as Gralnick's subtle behavioral changes and inconsistencies began to foreshadow that there was something wrong. "The most important thing people have to realize is at first the behavior changes and symptoms are subtle. At age 57, my husband presented atypically and was misdiagnosed twice; once for depression and once for stress."

The Daily Inconsistencies and Mood Changes

Meryl describes how many of the Alzheimer's behaviors can be confused with everyday maladies. And people suffering from the disease are often in denial. "He was a scientist. He could pick one paper out of a stack and know exactly what it was. He was meticulous and suddenly became disorganized and began to work harder to hide things." Gralnick was very young at 55 when evidence that something was 'off' became apparent; he couldn't remember where to sign a check and lost his place in a speech to 400 other doctors. The everyday things we all take for granted were no longer simple.

According to Ms. Comer, the hippocampus, or structure in the brain that is involved in the processing of emotions and memory, goes into overdrive in the beginning stages of the disease. "We may all joke about a senior moment, but it is only because the fear of loss of mental capacity is overwhelming and why smart people hide out for a very long time." Often times, people also "become more self-centered than usual," according to Comer. "Interactions with family and behaviors become more problematic because people with early symptoms are working so hard to compensate."

This first phase can be especially challenging and heart-wrenching, Meryl points out, since families often play into denial with their loved one, even though they suspect something is wrong. A proper diagnosis is often delayed two years from first symptoms.

Comer says negotiating rather than challenging their reality can be the most effective management strategy; otherwise there is a stalemate with no resolution. It is often much easier to redirect someone by persuading them that the action requested was their idea and you are here to help. It helps to defuse the trauma of the moment.

How Does an Alzheimer's Diagnosis Change Your Life?

Gralnick presented atypically for Alzheimer's; too young, too fit and too accomplished. This made it especially challenging for Comer. "It's not only a very irrational disease, but also very hard to take away someone's independence. I actually had to dismantle the battery and lock away his sports car in the garage to protect other people," she comments. But you must be pre-emptive so they don't endanger themselves and others. Let the doctor make the call that it's time to turn over the keys to the car; otherwise you become the victim of your loved one's rage."

Comer made sure to take precautions and put up signs around the house to help her husband. "If you go back almost 20 years, Alzheimer's was not a public topic of conversation. The diagnosis envelops you like a dark cloud. You feel helpless and alone. No one is prepared to be handed a diagnosis for which there is no cure. Alzheimer's rob the patient and his family of a future."

Comer was forced to leave her career and she worries it's a fate awaiting many women in their late 40s currently in the workforce. The diagnosis changed her life forever. Alzheimer's presents a "dependency and intensity of care that no one anticipates. The well spouse is the anchor for the spouse that is sick; they follow you around everywhere. You're their surrogate. It's like having a shadow." Care gets no respect in this country; no wonder we're in crisis.

The Future of Alzheimer's

Comer was recruited by Geoffrey Beene Foundation trustee, Tom Hutton, to design and lead an Alzheimer's Initiative using the lens of her advocacy around early diagnosis to mirror the cutting-edge research at the Geoffrey Beene Cancer Research Center at Memorial Sloan Kettering. She says she was proud to join a company because 100% of the net profits of this international designer menswear brand fund critical causes. "I needed to flip the pain and refocus on making certain my experience wasn't repeated by other families. Our baby boomer generation needs to take on the challenge of curing Alzheimer's as a legacy issue. I don't want my son taking care of me the way I have taken care of my husband and now my mother; it destroys relationships. The pain of Alzheimer's is that you watch someone disappear in slow motion. It happens before your eyes – the loss of dignity, independence, and the very essence of who they were as a human being."

Comer points out an interesting perspective of how humanity is affected by the debilitating disease. "We're really a composite of our life experiences -memory layered upon memory and Alzheimer's steals that away." A recent example of the importance of memories and the human experience is [Hurricane Sandy](#), she relays. "People were salvaging family pictures out of the rubble of their homes as a lifeline to memories of their past — memories that grounded and connected them even amidst disaster."

The Importance of Early Diagnosis

Comer has set the focus of the Geoffrey Beene Foundation Alzheimer's Initiative around early diagnosis. "This is the biggest women's issue since breast cancer. We outlive men statistically and we're more prone to get it through researchers don't know why. Not only that, but women across ethnicities are the primary caregivers. With the baby boom generation turning 65, there's an epidemic headed our way. This will be especially hard for those in the [sandwich generation](#)."

"People are turning age 65 at the rate of 10,000 a day," says Comer. "Women who fought hard to get into the workplace will now be forced out to take care of loved ones with this disease." She believes baby boomers need to sign up for prevention trials to help accelerate research to find a disease modifying drug. It is a difficult conversation because poll results show that baby boomers, as a generation, like to believe they're "ageless."

Alzheimer's Disease Costs \$200 Billion A Year, But People Are Still Ignorant

Comer has been especially frustrated with how Alzheimer's disease had been covered in the media." It is devastation glossed over. One out of three Americans are impacted in some way by Alzheimer's disease, but they don't want the details. Alzheimer's is not about a little old lady who forgets her address," says Comer. "In reality, it's the cruelest of disease." It really has only been in the past 10 years that the public awareness of Alzheimer's disease discussion has begun, even though Alzheimer's care costs \$200 billion each year, according to the [Alzheimer's Association](#).

“We need to wage a war on Alzheimer’s, just as we did with Cancer,” says Comer. “We need options around the disease. Baby boomers need to say the disease is ‘unacceptable for our future.’”

Comer argues, “***How can the government spend 200 billion dollars annually on care and less than 1% on research? We need to be on the fast track for therapies like HIV/AIDS and Cancer.***” This savvy lady points out that if you’re 60, changes in the brain are probably happening around 40. This is why research needs to start on people much younger. Comer believes that we need to give people who have the disease quality of life. Slowing the progression, even if by 5 years, will help. “You’re giving people more quality of life and saving society billions and billions of dollars” if we can find appropriate disease modifying therapies.”

Helping to Alleviate What Alzheimer’s Does to the Caregiver

The intensity of Alzheimer’s care is ridiculous. Comer realized she had post-traumatic stress after she attended a conference that discussed post-traumatic stress in returning veterans. She realized she had been hyper vigilant for 18 years. Not only that, circadian rhythms get thrown off as caregivers deal with [Sundowner’s Syndrome](#). And if Alzheimer’s research could just get a little further — or a cure found — many of these problems could be avoided. “Nothing prepares you for this disease. No one is prepared for the isolation. Friends disappear because the person they knew is no longer there. The caregiver gets trapped with the patient. It is very lonely and isolating,” notes Comer. Support groups don’t work for everyone – either because they are not age appropriate or because the cost to replace yourself for time away from the patient is prohibitive. It’s really a double-edged sword, she conveys. “You need something to brighten your spirit.” Comer’s grandchildren and women friends saved her as they were her “antidepressant of choice.” She recalls friends saying to her, “We’ve got to get you out to breathe.”

Being an advocate has helped Comer. “You have to have to shift the paradigm of defeat by ‘flipping the pain.’ Alzheimer’s disease is going to win. It will take my husband, but it will not take me. I’m going to fight for the next generation.”

What do you think about the looming Alzheimer’s crisis? Do you think there’s any way the government will reach their goal of curing Alzheimer’s by 2025, even after hearing the research and funding issues Comer describes above? We’d love to hear your thoughts in the comments section below...

About Meryl Comer:

[Meryl Comer](#) is an Emmy award-winning reporter, producer, moderator and talk show host with more than 30 years of broadcast journalism experience. She was among the first female broadcasters to specialize in business news as it relates to public policy. She is President of the Geoffrey Beene Foundation Alzheimer’s Initiative and organized Rock Stars of Science initiative.

Comer has spent the past 16 years as the at-home caregiver for her physician/researcher husband who was diagnosed with early-onset Alzheimer’s disease at the age of 58.

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About the Author

Dana Larsen is a senior living writer whose mission is to educate and empower caregivers and equip them with the resources and knowledge they need to not only care for their elderly loved ones, but also care for themselves.

On a personal note, Dana is mother to two bright-eyed, zealous children and helps as a caregiver for her vivacious and quirky 88-year-old grandmother who suffers from Alzheimer's. Her passions include dancing, yoga, traveling, good food and the arts. She graduated with honors from the University of Washington.