



WELLNESS | SPIRITUALITY

# Elevate

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HEALTH SPOTLIGHT

## *Forget Me Not*

EBONY EXAMINES HOW FAMILIES CAN BEST MANAGE THE ILLNESS THAT BREAKS SO MANY OF THEM APART

By TAMARA E. HOLMES

**W**hen Frank Self of Waxhaw, N.C., noticed that his wife, Shirley, was becoming more and more forgetful a decade ago, he didn't think much of it. But when she started getting lost while driving to familiar places, he became worried. After a battery of medical tests, Frank realized his concerns were justified. In 2008, at just 58 years old, Shirley was diagnosed with Alzheimer's disease.

Alzheimer's is a form of dementia in which brain cells become damaged and die over a period of time. As the disease progresses, one may experience memory loss, behavioral changes and an inability to communicate and connect with his or her surround-

ings. In the later stages, it can even affect biological functions such as the ability to swallow and mobility. The malady most commonly affects people over age 65; however, about 5 percent of those with the disease, like Shirley, get diagnosed even before then with early-onset Alzheimer's.

Since Shirley's diagnosis, the Selfs have been on a path that they never could have imagined. After learning she had the neurological disorder, Shirley stopped driving but maintained normal activities such as grocery shopping. But as the disease progressed, she needed help with such basic tasks as bathing, dressing and eating. Frank decided to retire from his job as a corporate accountant to take care of his wife full time. Today, →



at 64, she rarely speaks, yet her eyes light up when she hears the familiar voice of a friend or family member greet her over a speakerphone that's been set up to ensure that she remains connected to the outside world. Coming to grips with the love of his life's decline has been hard, but Frank knows that he's in for the long haul. "I elected to be a 24/7 caregiver, and I'm going to do that as long as the Lord lets me," says the 65-year-old, who makes sure to prepare his wife's favorite waffles and hold her hand as they walk around the house so she can get some exercise. "With this illness, it's not like a cancer where they judge things from a five-year survival rate; in fact, there is no survival rate," he laments. "There is no way out. Alzheimer's always wins."

### **A Growing Epidemic**

More than 5 million Americans currently live with Alzheimer's, and that number is projected to balloon to 16 million by 2050. It's the sixth-leading cause of death in the United States and fourth-leading cause of death for older African-Americans; about one-third of people over age 85 are diagnosed with the disease.

If you're African-American, you're twice as likely as a White person to develop Alzheimer's. Many Blacks dismiss instances of memory loss as part of the aging process rather than mention the episodes to their doctor. As a result, by the time they get diagnosed, "African-Americans with Alzheimer's may miss that crucial opportunity to make important legal, financial and health care plans while they're still capable and have the chance to make those preferences known to their family," notes Marshawn Brown, director of diversity and inclusion for the Alzheimer's Association, an organization that promotes research, education and support for those impacted by the disease.

The costs associated with treatment of the illness in the United States this year is a staggering \$214 billion, a number expected to rise to \$1.2 trillion by 2050. Blacks take on a disproportionate amount of the economic burden, says Stephanie Monroe, director of the African American Network Against Alzheimer's, which was formed to galvanize the Black community around the issue. A study commissioned by the group found that although Blacks only make up 13.6 percent of the U.S. popula-

tion, we bear over 33 percent of the overall cost of the disease. Most of these expenses are connected with caregiving, whether it's in the home or in a nursing home facility, with families spending as much as \$40,000 to \$50,000 a year to take care of their ailing loved ones.

Women are more likely to develop Alzheimer's than men. While studies suggest that genetics may play a role, another factor is that women tend to live longer, giving the disease more time to manifest.



### **Coping Mechanisms**

There's no cure for Alzheimer's. Medications can't reverse the condition, but they can help to mask symptoms, according to Monica W. Parker, M.D., an assistant professor of medicine in the Division of Geriatrics and Gerontology at Emory University in Atlanta.

For those in the early stages of memory loss, all is not lost. There can be years of normal living ahead. Carol Moore, 76, of Sandy Springs, Ga., was diagnosed in 2012 with mild cognitive impairment, a brain function disorder characterized by noticeable memory decline that boosts the risk of developing Alzheimer's. She still drives, lives independently and also counsels others about the disease's early stages. "Everyone thinks you're confined to a chair once you're diag-

nosed," says Moore, "but you're not suddenly days away from being in an institution."

Certain genes, including APOE-e4 and ABCA7, when carried by Blacks are believed to increase the chance of Alzheimer's. And many health conditions can raise your risk, such as obesity, hypertension and diabetes.

For that reason, a healthy lifestyle is key. "If you're in your 40s and 50s, you must maintain an ideal weight, keep your blood pressure low and your blood sugar under control," informs Parker.

### **Quest for a Cure**

A big challenge in finding a potential cure is coming up with better ways to identify the disease. "The way we currently diagnose Alzheimer's is when someone has significant memory loss," says Keith L. Black, M.D., chairman and professor of the Department of Neurosurgery for Cedars-Sinai Medical Center in Los Angeles. "The disease starts about 20 to 30 years earlier. By the time you get memory loss, you've already lost 40 percent of your brain cells. We might be able to find a treatment to stop that if we can identify brain changes years before."

Although scientists don't know just what causes Alzheimer's, it's believed that the accumulation of abnormal plaques of beta-amyloid, a toxic protein, and the tangled fibers of a protein called tau play a role. "One goal of the research is to find ways to reduce the accumulation of these toxic proteins and keep the tangles from developing in the hopes that it will prevent brain cells from dying," explains Black.

In order to test prospective treatments, there's a need not so much for those currently suffering as there is for people with a high risk of developing Alzheimer's to participate in clinical trials. Since family history is a risk factor, if you have a parent with the disease, your participation could help bring about a cure. One way to start is through TrialMatch, the Alzheimer's Association's program that connects patients, caregivers and healthy volunteers to clinical trials. Or you can visit [clinicaltrials.gov](http://clinicaltrials.gov).

For people like the Selfs (not pictured above) who've coped with the disease for years, the promising future of clinical trials is tempered by difficulties managing the condition. "God places problems on us for a reason," says Frank. "I don't know what it is, but I accept it and we keep moving forward."