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The Forgotten

WOMAN FINDS RAISING AWARENESS, SELF-CARE ARE KEY TO HELPING LOVED ONES WITH ALZHEIMER'S DISEASE

By YVELETTE STINES

We all have moments we can recall clearly. With some memories, the time, place, smell and other details return vividly and almost as if in color. These experiences can bring smiles or tears.

Now imagine if you had no recollection of your life. Imagine that the people you love most are now strangers, you can't conduct your daily activities without assistance and you can't recall some of your best experiences. This is life for some people with Alzheimer's disease.

COURTESY VERONICA FRANKLIN

Much of the narrative centers on how the memory-seizing affliction affects the elderly. But family members, caregivers, doctors and treatments all play roles in raising awareness.

Alzheimer's and dementia are often used interchangeably though they have different meanings. "When you think of dementia, think of it as a compilation of symptoms," explains Stephanie Johnson, who has a doctorate in cognitive neuroscience and is a clinical and research neuropsychologist based in Washington, D.C. "These symptoms can be changes in cognition, behavior and more. Dementia is an umbrella term, and Alzheimer's is one of the most prevalent forms of dementia."

According to Johnson, Alzheimer's is not simply occasional forgetfulness. "It's not like the memory issues we all encounter from time to time, like when you walk into a room and forget why," she says. "A person with Alzheimer's has difficulty remembering how to get to a familiar place, like the bank they've gone to for years; they can't recognize a familiar person, or they forget the name of a grandchild."

The average age of a person diagnosed with Alzheimer's is between 65 and 70. And though 1 in 10 persons 65 and older is diagnosed with the illness, African-Americans are twice as likely to have the disease. It is not clear how it is acquired, but risk factors include diabetes, hypertension and high cholesterol. "Our increased vascular risk factors may be a contributing factor to the higher diagnosis with African-Americans," Johnson adds.

To improve lifestyle, she suggests exercise and foods that are high in antioxidants and omega 3 fatty acids. "If it is good for the heart, it is good for the brain; studies show that exercise is very helpful for the brain," Johnson explains. "After two weeks of no exercise, there is a significant change of blood flow that goes to the brain."

According to a recent study, African-Americans who carry a variant of the ABCA7 gene also have a higher risk of Alzheimer's. Another risk factor is one form of the APOE gene, which is involved in cholesterol transport.

Veronica Shanklin with her grandmother and mom

COURTESY VERONICA SHANKLIN

Alzheimer's doesn't just affect the patient. Veronica Shanklin's life changed significantly after she moved back to Texas in April 2013 to care for her mother and grandmother. She had been living in Chicago, and during frequent visits home she noticed her grandmother was having issues. "My mom didn't identify my grandmother as having Alzheimer's at the time; she saw it as old age," Shanklin says. After her grandmother moved in with her mother, Shanklin began noticing her mother's ability to keep up with personal affairs was changing. It "was a culture shock. I was living in a condo downtown Chicago, had a decent job and a great social life," she adds. At the time of Shanklin's move, her grandmother was at the height of her Alzheimer's, so she had to immediately take on the personal, business and medical responsibilities of her grandmother and mother, in addition to her own. "It is very stressful to have to take this on and figure out the system, which is a mess, so my family can have the best care," she explains.

With her new responsibilities, Shanklin found an outlet at her local Alzheimer's association. "I started volunteering two days a week and helped with office duties. This kept me busy while I was figuring things out," she says. Through volunteering, Shanklin found a support group and now is on the board of the organization. She also started a blog, Vee, Myself and I (veemyselfandi.com), which raises awareness of Alzheimer's and encourages caregivers. Another project she is proud of is Faces of Care Warriors (facesofcarewarriors.com), an online photo gallery with stories of caregivers and their families.

Shanklin found resources within the support groups and local organization. "When my mom and I would go to a support group, it helped to know you are not alone," she says.

Though resources and treatments are essential, advances in cures have stalled. Stephanie Monroe, executive director of African-Americans Against Alzheimer's, a network of Us Against Alzheimer's, works to raise awareness of the issue. Monroe had just retired from the health and human services committee of the U.S. Senate, where she was chief counsel when she joined the board, and was shocked that there was so little progress. "This was not an issue that had been brought to our attention; it was upsetting that [at the time] there had not been a new medicine in 17 years," she says.

In addition to the lack of medication, funding for research was low. Thanks to lobbying efforts, "We are now seeing Congress pay attention and give us research dollars needed to see more effective treatments by 2020," Monroe says, adding that it is difficult to find a "treatment for African-Americans, specifically, because we haven't participated in research."

One of the ways that Monroe educates about Alzheimer's is through a play called *Forget Me Not*. "People remember what they experience, the emotion; we found this to be very effective," she says. The play engages the community via panel discussions and offers resources.

Alzheimer's is misunderstood, and education is key. "This is beyond a memory illness. Eventually, you can't remember your kids, your spouse; you forget the essence of who you are and things that meant so much to you," Monroe says. "Patients can become 100-percent dependent." This is why it is important that caregivers need to take care of themselves.