

## Education and Alzheimer's: Combating Stigma and Misinformation

Education helps us acquire knowledge to better understand the world around us and put the unknown into perspective. Through education we learn how to combat stigma; specifically the stigma surrounding Alzheimer's disease.

Alzheimer's disease is a type of dementia that affects the brain causing problems with memory, thinking, and behavior. It is the **6th leading cause of death** in the United States. As of 2020, over **94,000 Alabamians** are living with the disease. Despite the access to vast resources and information, once a person is diagnosed with the disease it is viewed as a death sentence. This is far from the truth!

Tremaine Davis, owner of Touching Hearts at Home, understands the significant role education plays in combating the stigma that overshadows Alzheimer's disease. He is a native of Madison, Alabama. He received his Bachelors in Human Resources from Athens State University and his Master's and Doctorate in Biblical Counseling from Birmingham Theological Seminary.

He is no stranger to Alzheimer's and the challenges it brings. His mother was a CNA for 25 years and he enjoyed watching his mother care for the elderly. Tremaine has spent about 15 years in the caregiving industry through a ministry and a family setting. "I help those in the community as they age and go through various challenges," he explained.

Both his aunt and great grandmother were diagnosed with the disease. He has dealt firsthand with the challenges brought on by Alzheimer's and how it affects the family dynamic on a day to day basis.

Alzheimer's is a complex disease still riddled with uncertainty. As the disease progresses, some patients may face drastic changes in personality, become more combative, and are more prone to wander off. All of which can cause stressful challenges to the caregivers, which are often close family members. In the state of Alabama, there are over **306,000** caregivers providing about **349 million hours of unpaid care**. The hours of unpaid care are estimated to value over **4 million dollars**.

Touching Hearts at Home provides a variety of services for those affected by Alzheimer's but there is one that is the key to combating the stigma surrounding Alzheimer's: education. Tremaine is a community educator for the Alabama Chapter of the Alzheimer's Association. He spends time going to senior centers, health fairs, hospitals, nursing homes, and any place that is willing to listen and learn about the disease. "Alzheimer's causes one to lose themselves, but the family members still know who they are," Tremaine said regarding the frustration that the disease causes.

Education turns a light on for most people. Caregivers often think they can control what a patient says or their actions, but they are fighting a losing battle. "What we don't know, we just don't know," Tremaine says. Education helps us develop a better understanding of the unknown, which goes hand in hand with Alzheimer's. "When we are competent we are also confident in what we are doing," Tremaine explained about the importance of education.

Despite age, socioeconomic status, or race, everyone needs to get educated and try to understand the disease better. When there is misinformation, stigma is inevitable. There are various options to educate oneself whether its taking an online class through the Alzheimer's Association website or through a local support group, there is something out there for everyone. Alzheimer's research is advancing each day. There are medications and treatments to help patients enjoy and live a quality lifestyle.

"People want to put mother and father in the closet and that is not the answer. We must rid ourselves of the stigma that life is over or we can't enjoy ourselves or that we can't have conversations based on a diagnosis. Education is going to help families understand Alzheimer's better. If a family member is not educated on the disease, they are not helping the situation," he explains.

Institutions like the University of Alabama at Birmingham (UAB) and organizations like the Alzheimer's Association are working hard to find a cure or even develop ways to manage the disease better in the long run. Places like Touching Hearts at Home also provide families the opportunity to continue to build memories and stay active together while providing comfort that their loved ones are in good hands.

One thing Tremaine wanted to make clear was that Alzheimer's disease is not a black or white issue. The disease itself does not discriminate, but there are some communities disproportionately affected.

According to the Alzheimer's Association 2019 Facts and Figures Report, African Americans are two times more likely to develop Alzheimer's than their white counterparts. Despite their increased risk, it is estimated that 97% of participants in industry-funded clinical trials and more than 90% in NIH-funded trials for Alzheimer's disease are comprised of non-Hispanic whites.

The question is how do we help raise awareness about Alzheimer's in underrepresented communities and ensure they have access to resources to help manage the disease? Tremaine offered a few suggestions on how Alzheimer's awareness can be raised within the African American community and increase interest in Alzheimer's prevention.

The problem (Alzheimer's risk factors) has been identified and now it is a matter of engaging with the African American community to make sure they are getting this information. Tremaine suggests engaging directly with the community, churches, neighborhood watch groups, and even grocery stores to spread awareness. "Everyone goes to the grocery store so why not put up a poster with information or even put it on a milk carton," he said.

We must rebuild trust within the African American community. Distrust has built over the years due to African Americans being mistreated and deceived for the sake of research (i.e Tuskegee Trials). Tremaine explained that confidence will be built through trustworthy individuals like doctors. We must ensure that doctors are equipping patients with information about the disease. We should not be acting just when there is a diagnosis, but being proactive instead.

The risk factors that can increase the likelihood of developing Alzheimer's include: age, socioeconomic status, poor nutrition, cardiovascular disease, physical activity, or even lacking access to quality healthcare. A few of these risk factors are more prominent in African American communities.

"People are just not aware and we owe it to Alabama and to the black community to lower or at least balance the playing field when it comes to the prevalence of Alzheimer's in certain communities," Tremaine said. We all need to play our part, educate ourselves, and help get this information out into our communities. Be aware of risk factors and symptoms and share this information with those who may need it most.

At the end of the day, we are all human beings and could potentially be affected by Alzheimer's in the future. It is important that families understand that they are not alone as they embark on this journey. It is easy to think that no one understands the challenges of the disease and they opt to isolate themselves from others. There are resources available like the Alzheimer's Association and Touching Hearts at Home that are helping families navigate the disease. No one is ever alone.

Tremaine is doing his part to make sure all communities are receiving the proper education to be able to diagnose the disease sooner. Now it is time for everyone else to do their part in raising Alzheimer's awareness. For more information on how you can help raise awareness, volunteer, or learn more about resources available to those affected by Alzheimer's, please visit the Alzheimer's Association website at [www.alz.org/al](http://www.alz.org/al). To learn more about **Touching Hearts at Home** and its services, please visit <https://www.touchinghearts.com/birmingham/> or call **205.413.6354**.