

The Alzheimer's Advocate Guide

Statistics show that older African Americans are twice as likely to develop Alzheimer's Disease than older White Americans. 21.3% of African Americans 70 or older live with Alzheimer's disease.

Doctors and scientists point to higher rates of diabetes and hypertension as possible drivers, but also note the effects of African American culture and lifestyle, access to quality health care, and delays in seeking treatment due to a distrust of the medical community as contributing factors. In fact, more than 80 percent of African Americans say they face barriers to accessing quality health care and support, and half say they have experienced discrimination while seeking care for a person living with Alzheimer's.¹

Although older Black and Hispanic Americans are more likely to have Alzheimer's or other dementias than White Americans, fewer participate in research or clinical trials. Without participation by Black, Hispanic, Asian, Native Americans and other people of color, a complete understanding of how racial and ethnic differences may impact potential new treatments is impossible.² Social justice demands that new treatments are safe, available, and effective for communities of color.

The key to reducing the risk of Alzheimer's disease within the African American and POC communities begins with trust, education and encouraging participation in research studies and clinical trials. This education is best delivered by people and sources that are trusted within the community—people like you.

If you have experienced dementia or Alzheimer's Disease as a caregiver or patient and are interested in doing more, consider joining our efforts as community educators.

Meet Mollie and Ralph Richards

Mollie and Ralph Richards have spent the past 25 years dedicated to educating members of the African American community about Alzheimer's Disease through their unique community engagement model. Through one-to-one discussions, work with local community groups, and participation in community symposiums, their aim is to help patients and caregivers in the African American community manage the disease, and to encourage participation in clinical trials and studies so that effective solutions and therapies can be identified and proven to work for the African American community.



To connect with someone or volunteer in your community, contact your local Alzheimer's support organization.

¹ Alzheimer's Association

² Memory Advocate Peers

Becoming a Community Educator

● **Begin by educating 1:1.** Gather facts about the disease and share your personal experiences as a patient or caregiver. Develop an “elevator speech” - a quick one-minute summary about your personal passion for educating about Alzheimer’s Disease.

What did you learn through your experience? What barriers did you have to overcome? What advice would you give to someone early in this journey? Talking about your personal experience will build trust, help others feel more comfortable sharing their journeys, and reduce the stigma of speaking openly about it. It’s important to be empathetic and sensitive when telling personal narratives.

● **Understand the community you want to reach.** Attend activities in the community to better understand the culture, barriers, views and needs. It takes time to build trust as you get to know the community and they get to know you. Offer to participate in educational programs, Town Hall meetings, health fairs or related community events being sponsored by others. Family reunions are great opportunities to educate as well.

● **Host educational events in partnership with trusted community groups such as churches.** Churches are a great place to connect with the African American community. People of color trust the church because it’s a source of refuge.

Get to know the Senior Pastor and share your personal story. He may appoint someone from the Health Ministry or other designee to be the point person for the project.

The first experience may be a “Purple Sunday” or “Go Purple” Sunday in which you deliver a short 5–6-minute talk in front of the congregation which begins with transparently telling your story, explaining the problem, sharing facts, and finally discussing ways people can help. Be sure to have a table of resources set up in a designated area to answer questions and distribute materials after the services. Ultimately, the goal is to deliver an in-depth presentation or a series of presentations to the congregation.

● **Form a local Community Advisory Board.** Composed of a variety of people from the community, the goal of a Community Advisory Board is to extend your reach. The volunteer board should consist of pastors, staff from the Department of Health, nurses, attorneys, retirees, business owners and social workers. The CAB may also be supported by the addition of statisticians, recruiters and outreach coordinators.

● **Form partnerships with other established and trusted community groups.** To expand your reach, share your educational mission with existing groups that interact with the African American Community, such as the NAACP, the National Council of Negro Women, Greek organizations, AARP, The Urban League, the Red Cross, the National Kidney Foundation, the American Heart Association and/or 100 Black Men Organization.

● **Contact local media or create your own.** Reach out to print, radio and television media and offer to contribute content and resources. Create podcasts and use social media to share facts, insights, presentations, resources and details about upcoming events. Offer to participate on panel discussions.