Diane Powell understands what it’s like to watch a friend slip away.

Tina, a close friend whose last name she did not reveal, died from Alzheimer’s disease in her early 70s, just two years after its onset. Ms. Powell says her decline was rapid, radical and disturbing. By the time the progressive brain disease fully took hold, a woman renowned for her cooking skills could barely remember how to make a pot of coffee.

“We could see the fear in her own eyes that she realized at certain points that her conversation was disjointed and no longer made sense,” Ms. Powell said. “She went from being a very vivacious, educated, professional woman who was very talkative and connected with the community to becoming very, very quiet and going into a shell.”
Ms. Powell, of Mt. Lebanon, is chair of the Pittsburgh chapter of Black Women for Positive Change, which advocates for education, affordable health care and anti-violence in the Black community. This was her first experience with Alzheimer's disease.

Multiple studies have revealed widening disparities between Black Americans and white Americans in the prevalence and treatment of Alzheimer's at a time when more people are at risk. According to the Census Bureau, 16.5% of the U.S. population is 65 years or older, the age when symptoms of Alzheimer's typically begin to appear. By mid-century, that demographic is expected to reach 22%.

That’s why Ms. Powell and the Alzheimer’s Association have decided to team up for a campaign to connect local Black residents with the tools to seek treatment and support for the disease — before it’s too late.

**Racial disparities**

A 2018 study conducted by the Chicago Health and Aging Project suggested that Black Americans are nearly twice as likely to develop Alzheimer’s compared with white Americans, and that the disease is underreported within the Black community. In an 18-year study of 10,802 individuals age 65 and older, Black participants were found to have a 1.9 times higher risk of developing Alzheimer’s.

The study, in which 64% of the participants were Black and 36% white, looked at cognitive function decline and both prevalent and developing dementias. After an initial clinical evaluation, it was determined that 19.9% of Black participants had a weighted prevalence of Alzheimer’s compared to 8.2% of white participants.
According to the study, educational attainment plays a role. The study mentions racial disparities in educational achievement in the United States as a contributing factor, with socioeconomic circumstances such as poverty and poor-quality schools widening the gap between Black and white Americans.
“There is a reasonable body of evidence to suggest there may be cognitive health disparities disproportionally impacting African Americans,” said Dr. Jennifer H. Lingler, a researcher at the University of Pittsburgh who serves on the executive committee of the Alzheimer Disease Research Center.

She said it is difficult to draw conclusions from the data because racial disparities are not just prevalent in Alzheimer’s diagnoses, but in research studies, too. A 2020 study published by Dr. Lingler and members of the Alzheimer’s Disease Research Center noted that Black Americans make up just 5% of participants in clinical trials and autopsies related to the disease.

“Our perspective in Pittsburgh is that much of the research is flawed because African Americans have been so underrepresented in clinical research,” Dr. Lingler said, “especially clinical research in Alzheimer's disease.”

The study also found that Black Americans are often diagnosed with Alzheimer’s later, receive treatment later than people of other races, and pay more out of pocket for dementia-related medical care.

**A lack of trust**

In May, Black Women for Positive Change and the Alzheimer’s Association Greater Pennsylvania Chapter held a virtual forum of over 30 health care providers, faith leaders, researchers and community members. Stories were shared, connections were made and solutions were discussed — all with hopes of reducing these racial disparities.

A key takeaway from the forum was that Black Pennsylvanians were reluctant to report symptoms and seek treatment for Alzheimer’s due to a lack of trust in the health care system after generations of discrimination.

“Not just here in Pittsburgh, but nationwide Black Americans lack that trust in research and clinical trials, and half of them doubt that Alzheimer’s treatments will be shared with them,” said Sara Murphy, vice president of programs at the Alzheimer’s Association Greater Pennsylvania Chapter.

“In combination with that, it’s true, unfortunately, that discrimination is a barrier to Alzheimer's care, and that about half of Black Americans report that they’ve experienced some type of health care discrimination,” she added.
In an October 2020 poll conducted by the Kaiser Family Foundation of 777 Black Americans, 70% said the health care system treats people unfairly based on race “very often” and just over half of respondents said they had trust in local hospitals. A 2021 Facts and Figures report from the Alzheimer’s Association included a survey of 2,491 U.S. adults — 515 of them Black — and found that 36% of Black respondents believed discrimination would be a barrier to receiving treatment for Alzheimer’s.

Ms. Powell said wariness extends beyond Alzheimer’s patients to their family members. The report concluded that among non-white caregivers, over half were concerned that “providers or staff do not listen to what they are saying because of their race, color or ethnicity.”
Black Americans’ distrust in healthcare system and Alzheimer’s research

**RACE/ETHNICITY**

<table>
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<th>Important for Alzheimer’s or dementia health care providers to understand a (race/ethnicity) person’s ethnic or racial background</th>
<th>Hispanic</th>
<th>Black</th>
<th>Asian</th>
<th>Native American</th>
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<tr>
<td></td>
<td>85%</td>
<td>89%</td>
<td>84%</td>
<td>92%</td>
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<tr>
<td>Confident that (race/ethnicity) patients currently have access to providers who understand their ethnic or racial background</td>
<td>59%</td>
<td>48%</td>
<td>63%</td>
<td>47%</td>
</tr>
</tbody>
</table>

**BIAS IN RESEARCH**

Percentage of American adults who believe medical research is biased against people of color:

- White: 31%
- Hispanic: 36%
- Black: 62%
- Asian: 45%
- Native American: 40%

Percentage of American adults who trust an Alzheimer’s cure will be shared equally regardless of race, color or ethnicity:

- White: 75%
- Hispanic: 66%
- Black: 53%
- Asian: 69%
- Native American: 65%

**DISCRIMINATION IN CARE, AMONG CAREGIVERS**

Percentage who believe discrimination would be a barrier to receiving Alzheimer’s care:

- Black: 36%

Percentage among non-white caregivers who say they have faced discrimination when navigating health care settings for their care recipient:

- Black: 42%
Daughter to caregiver

Jacqueline Winsett Ruple, a retired nurse practitioner who lives in Point Breeze, attended the virtual forum in May not just as a professional but as a caregiver. She has a doctorate in health administration.

“I’ve worked in this area, but I never had to be on the other end,” she said in a phone interview.

Her father, Joseph Winsett, developed symptoms of Alzheimer’s disease when he was 82 years old. The retired pastor of Ebenezer Baptist Church started to forget events that had just happened and began to make inappropriate comments about others in social situations. His wife, Jacqueline Winsett, would find him wandering aimlessly around their house at night.

For a year, his condition was known only to Ms. Winsett Ruple and her mother. Ms. Winsett Ruple was still working at the time, often until 8 p.m., and remembers coming home to immediately begin her next shift — the nightlong care of her father.

“Because I’ve taken care of patients who have been through this and I’ve counseled people, I thought I was ready. But I was not ready. All my knowledge that I had obtained does not really prepare you to deal with your family member and with your parent,” she said.

“I wasn’t ready to give up my role as his daughter,” she added.
Family strain

Ms. Winsett Ruple’s mother initially made excuses for her husband, though she eventually came to terms with his disease. One day, she followed his car and found him driving through red lights and stop signs. His license was revoked and the battery removed from his car.

Ms. Winsett Ruple said her brother and sister had a hard time accepting that their father had Alzheimer’s, even when she pointed out his inappropriate comments.

“My sister would say, ‘Well, he’s just joking.’ But I said, ‘That’s not something to joke about.’ So they were thinking that I was
overexaggerating, that I’m always looking and analyzing things too much. It became a very tense situation with me and my siblings.”

Her brother now lives out of state, and her sister recently began to help with their father’s care, Ms. Winsett Ruple said.

Eventually, Ms. Winsett Ruple was able to convince both of her parents to sign up for an Alzheimer’s research study at UPMC Presbyterian.

“We went to the research site, and there was not one African American there,” she said. “My mother was very wary.”

“I’ve known people in my neighborhood who are showing signs, you know, having problems, but the family does not want to discuss it. They don’t want to go to a doctor because they’re always trying to give people more medicine, or say, ‘They just need more rest’ and things like that. So there’s a big distrust there,” Ms. Winsett Ruple added.

Decades of discrimination

Ms. Powell understands the distrust of hospitals and medical staff in the Black community. When she was 2 years old, she accidentally swallowed a poisonous substance and needed urgent care.

“My mother rushed to the hospital, but was turned away,” she said.

Her mother was told to have the toddler drink milk to make her throw up. Another hospital finally admitted her and pumped her stomach.

“I could have easily not survived this experience and been another statistic,” Ms. Powell said. “These experiences were not uncommon in the Black experience.”

Reaching out

Black Women for Positive Change and the Alzheimer’s Association are now working together to rebuild trust in the Black community. Using information gathered from the forum, they have started an awareness campaign. Ms. Murphy said church and faith leaders have emerged as highly respected sources of medical education and support.

They have partnered with Rev. Brenda Gregg of the Project Destiny Faith-Based Health Collaborative and Pastor Richard W. Wingfield of the Pennsylvania Interfaith Impact Network to reach local congregations.
The University of Pittsburgh’s Alzheimer’s Disease Research Center is also trying to better connect Black Americans with education and resources to spot and treat Alzheimer’s disease in its early stages. Dr. Melita Terry, a member of the center, offers a monthly support group on the last Tuesday of each month for family and friends of individuals with Alzheimer’s disease and related dementias. Previously held in the Hill District, it’s been virtual since the COVID-19 pandemic began.

In September, members of Dr. Lingler’s team sat down with Black Pittsburghers to better understand what educational tools would connect with their community and encourage participation in Alzheimer’s research. Dr. Lingler was surprised to find that among the 14 participants, there was a notable sense of altruism, that they were participating in research not just for themselves, but for future generations.

“People talk about doing this to honor family members who have suffered from Alzheimer’s disease and other dementias,” Dr. Lingler said.

A motivating factor? “I don’t want my children to suffer.”

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