Dementia-related stigma perceived as:
* social rejection
* internalized shame
* social isolation
* financial insecurity

Associated with:
* low self-esteem
* isolation
* poor mental health
* decreased quality of life
* Relationship changes
* avoidance of help-seeking behaviors
  * delaying the diagnosis and utilization of health and social services
The Experience of Stigma
(Alzheimer’s Association)

• A diagnosis may test friendships. Friends may refuse to believe your diagnosis or withdraw from your life, leaving a feeling of abandonment or isolation.

• Relationships with family may change. Family members may not want to talk about the disease, perceive you as having little or no quality of life, or may avoid interacting with you.

• Others may approach your care partner to ask about you rather than asking you directly how you are doing.

• The reaction of some friends and family to your diagnosis may prevent you from seeking help from others.
Factors associated with Stigma

• Ageism
• Ignorance
• Fear
• “War” metaphors for confronting this “epidemic”
• The “Alzheimerization” of the dialogue to support Euthanasia
• Negative terminology (e.g., “wandering” vs. “walking about” and “challenging behaviors vs. “change in behaviors”
• Defining “self” in relation to cognitive function (“I think therefore I am”))
Alzheimer’s disease is now part of your life, but it doesn’t have to define who you are.

Your identities are often defined by what we do rather than how we are. The qualities that make each person unique represent a range of domains from physical traits to our relationships with others.

The diagnosis of Alzheimer’s or another dementia may impact how you see yourself. Only you can decide how much you will allow the disease to be part of who you are.

At the end of this activity, you will see how you are more than our diagnosis.

I AM MORE

Let’s Get Started!
You Are More Than Your Diagnosis

Profession
SELECT OR ENTER THE WORDS THAT BEST DESCRIBE YOUR CURRENT OR PREVIOUS PROFESSIONS.
You may select or enter up to 5 responses.

Teacher  Construction Worker
Homemaker  Executive
Enter your own response  Enter your own response
Enter your own response  Enter your own response

You Are More Than Your Diagnosis

Talents & Hobbies
SELECT THE WORDS THAT BEST DESCRIBE YOU, OR ADD YOUR OWN CUSTOM RESPONSES.
For best results, select or enter up to 5 responses.

Runner  Photographer
Woodworker  Gardener
Enter your own response  Enter your own response
Enter your own response  Enter your own response

You Are More Than Your Diagnosis

Relationships with Others
SELECT THE WORDS THAT BEST DESCRIBE HOW YOU IDENTIFY YOUR RELATIONSHIPS WITH OTHERS, OR ADD YOUR OWN CUSTOM RESPONSES.
For best results, select or enter up to 5 responses.

Partner  Grandmother
Friend  Neighbor
Enter your own response  Enter your own response
Enter your own response  Enter your own response

You Are More Than Your Diagnosis

Personality Traits
SELECT THE WORDS THAT BEST DESCRIBE YOU, OR ADD YOUR OWN CUSTOM RESPONSES.
For best results, select or enter up to 5 responses.

Funny  Shy
Adventurous  Easy Going
Enter your own response  Enter your own response
Enter your own response  Enter your own response

Enter your own response  Enter your own response
Dementia–related Disparities

African Americans Against Alzheimer’s

“Of all the forms of inequality, injustice in health care is the most shocking and inhumane.”
— Dr. Martin Luther King, Jr.

Addressing the Disparities Impact of Alzheimer’s on Communities of Color and Women
UsAgainstAlzheimer’s Center for Brain Health Equity

Learn More

5.7 million
Americans currently have Alzheimer’s disease.

20%
of Americans with the disease are African Americans, and they bear 33% of its national cost.

4th
Alzheimer’s is the 4th leading cause of death among older African Americans.

The Costs of Alzheimer’s and Other Dementia for African Americans

The economic burden of Alzheimer’s and other dementias for African Americans was $7.1 billion in 2017. Caring for African Americans with AD represents the bulk of these costs—more than 60%. More than 66% of the costs are borne by the families of African American women with AD, and close to half of the costs are concentrated in the
African American individuals with dementia have:

- higher rates of hospitalization
- more frequent hospitalizations
- greater severity of illness,
- longer lengths of stay
- higher readmission rates

Controlling for age, gender, ethnicity, education, cognitive status, and comorbidities, African American participants with dementia had worse admission physical function scores, more delirium, and more depressive symptoms as compared to White individuals.

Theoretical /Conceptual Considerations: Cumulative disadvantage and life course theories/structural racial discrimination

Interventional considerations: informed and adaptive
References and Resources

• Alzheimer’s Association website  https://www.alz.org/help-support/i-have-alz/overcoming-stigma