**Understanding Dementia:
Impacts on Diverse and Inclusive Populations**

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**Disclosure of Financial Relationships**

We do not have any relevant financial relationships with any commercial interests related to this talk

(Bruno's kids have all his money anyway. Ditto for Kate).

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Vision: A world without
**Alzheimer's and
all other dementia®.**

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Mission:

The Alzheimer's Association leads the way to **end Alzheimer's and all other dementia** — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

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**Strategic goals**

Providing and enhancing care and support.

Accelerating research.

Increasing concern and awareness.

Strengthening diversity, equity and inclusion.

Advancing public policy.

Increasing revenue.

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**Local Care and Support**

- 24/7 Helpline  1.800.272.3900
- Support Groups
- Education Programs
- Care Counseling
- Social Engagement
- Early Stage Programming
- Clinical Trial Matching Service
- Online Resource Finder and Message Boards
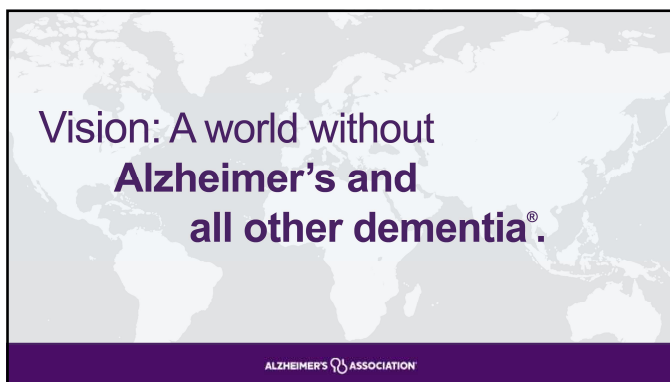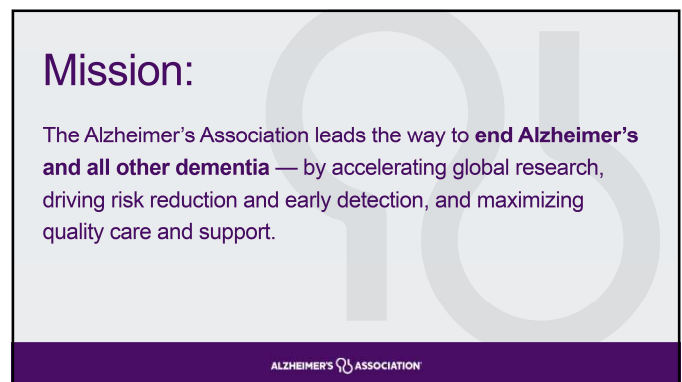- Respite Scholarships

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## Slide 7

### Local Commitment to Diverse Communities

- 24/7 Helpline available in over 200 + languages
- Programs translated into Arabic and Spanish
- Dedicated programming and outreach managers to:
  - Black/African Americans
  - Hispanic and Latino/Latina Americans
  - Middle Eastern North African Americans
  - Jewish Americans
  - People Living with HIV
  - LBGTQ+
  - People with Intellectual/Developmental Disabilities
  - Veterans

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## Slide 8

# Dementia Facts

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### TYPES OF DEMENTIA

Dementia is an umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.

- Alzheimer's
- Vascular
- Lewy body
- Frontotemporal
- Other, including Huntington's
- Mixed dementia: Dementia from more than one cause

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## Slide 10

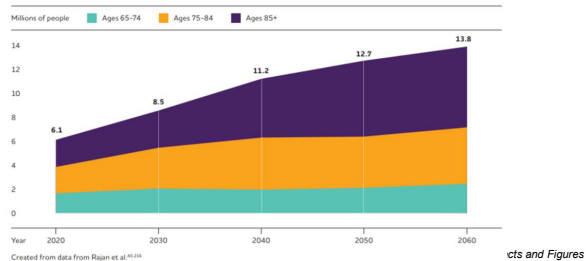More than **7 million** Americans are **living with Alzheimer's**.

By 2050, this number is expected to rise to nearly **13 million**.
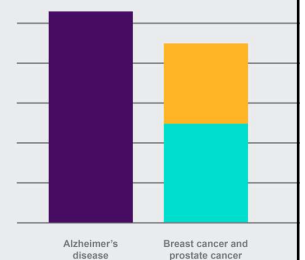
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## Slide 11

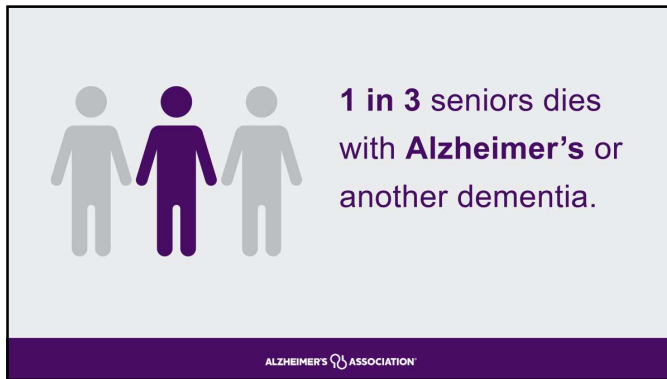### Projected Number of People Age 65+ in the U.S. Population with AD

Millions of people    Ages 65-74    Ages 75-84    Ages 85+

6.1    8.5    11.2    12.7    13.8

Year    2020    2030    2040    2050    2060

Created from data from Rajan et al.⁴⁰,²¹⁶

*cts and Figures*

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## Slide 12

**Alzheimer's** kills more people than breast cancer and prostate cancer **combined.**

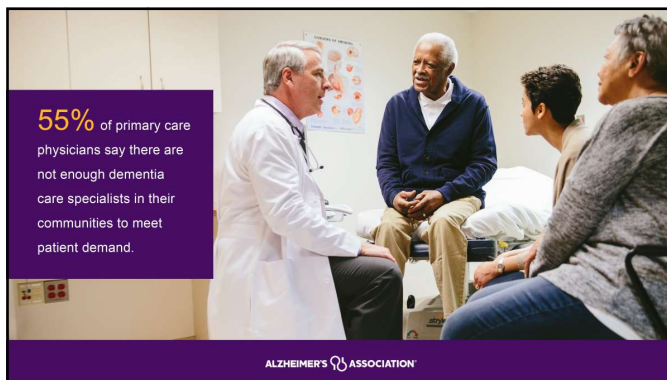Alzheimer's disease        Breast cancer and prostate cancer

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**1 in 3** seniors dies with **Alzheimer's** or another dementia.

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Between 2000-2021, deaths from **heart disease** have **decreased 2.1%** while deaths from **Alzheimer's disease** have **increased 141%.**

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**55%** of primary care physicians say there are not enough dementia care specialists in their communities to meet patient demand.

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**Rate of Screenings at Medicare Annual Wellness Visit**

(Bar chart with y-axis from 0 to 100 in increments of 10)

- Blood Pressure
- Cholesterol
- Vaccinations
- Hearing or Vision
- Diabetes
- Cancer
- Cognition

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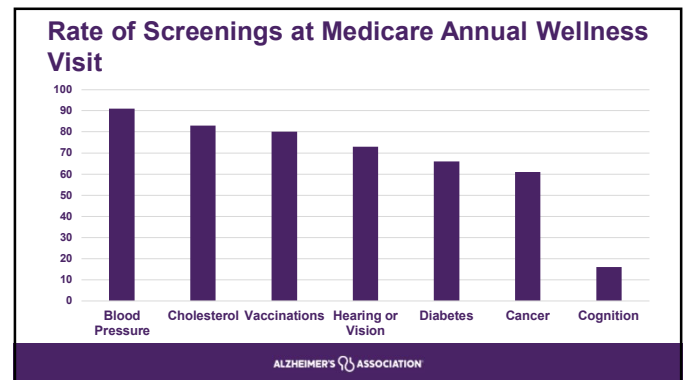**Who Should be Evaluated For Cognitive Impairment?**

**Per the Alzheimer's Association:**
- Individuals with memory concerns or other cognitive complaints.
  - Non-memory triggers include personality change, depression, deterioration of chronic disease without explanation, and falls or balance issues
- Informant reports of cognitive impairment, with or without patient concurrence
- Medicare beneficiaries, as part of the Annual Wellness Visit

**Per the US Preventative Services Task Force 2014 Recommendations:**
- "For asymptomatic, community-dwelling adults 65 years and older. There is insufficient evidence to recommend for or against screening for cognitive impairment. Clinicians should remain alert to early signs or symptoms of cognitive impairment (e.g., problems with memory or language) and evaluate as appropriate."

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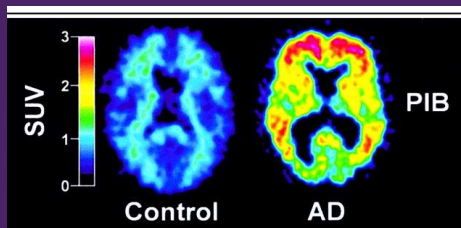**Cognitive Testing is Just One Piece of the Puzzle**

- Routine medical history and physical examinations is insufficient
- Cognitive testing is important particularly for older adults with cognitive concerns
- Impaired score must be taken in context of the clinical history and collateral information
  - Ceiling effects for younger and highly educated patients
  - Test characteristics (sensitivity and specificity) are less well defined for non-Alzheimer's etiologies
  - Possibility of false-positive results (less education, different cultural backgrounds, or tested in non-native language)

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# AD Neuropathophysiology

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## Pathological Hallmarks of Alzheimer's disease



Alzheimer cells
healthy cells

Amyloid plaques

Tau and Neurofibrillary Tangles

Tau tangles

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## "Amyloid Cascade": Pure Model



Increased brain amyloid

Amyloid deposition — Amyloid deposited

Inflammation, oxidation

Tangle formation — Neuro-degeneration: Cells start to dysfunction

Loss of neurochemicals and nerve cells — Cells begin to die (Usual time of diagnosis and current treatment)

Brain with AD

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## Slide 25

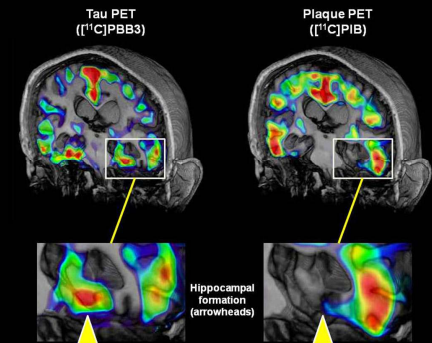**Brain Imaging: PiB Scanning, Identifying the Earliest Signs**



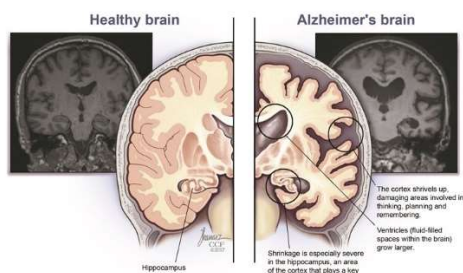Researchers have developed compounds (PIB) that bind to amyloid and allow plaques to be "seen" with brain imaging

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## Slide 26

**Tau lesions and senile plaques in Alzheimer's disease**



Tau PET ([¹¹C]PBB3)     Plaque PET ([¹¹C]PIB)

Hippocampal formation (arrowheads)

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## Slide 27



Healthy brain    Alzheimer's brain

The cortex shrivels up, damaging areas involved in thinking, planning and remembering.

Ventricles (fluid-filled spaces within the brain) grow larger.

Shrinkage is especially severe in the hippocampus, an area of the cortex that plays a key role in formation of new memories.
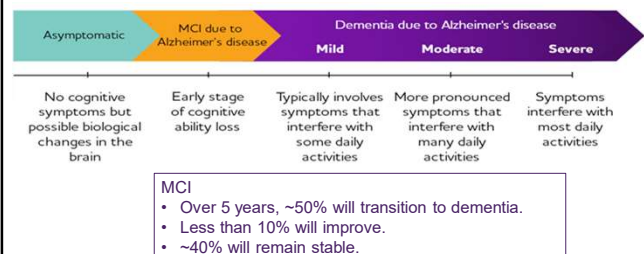
Hippocampus

MRI scans (gray) and illustrations (color) show the differences between a brain affected by Alzheimer's disease and a normal brain.
https://www.keepmemoryalive.org/brain-science/alzheimers-brain

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**Alzheimer's Disease is a Continuum**

Asymptomatic | MCI due to Alzheimer's disease | Dementia due to Alzheimer's disease — Mild, Moderate, Severe

| Asymptomatic | MCI due to Alzheimer's disease | Mild | Moderate | Severe |
|---|---|---|---|---|
| No cognitive symptoms but possible biological changes in the brain | Early stage of cognitive ability loss | Typically involves symptoms that interfere with some daily activities | More pronounced symptoms that interfere with many daily activities | Symptoms interfere with most daily activities |

MCI
- Over 5 years, ~50% will transition to dementia.
- Less than 10% will improve.
- ~40% will remain stable.

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**Risks for Dementia Include**

**Strongest Risk Factors**
- Age
- Down Syndrome
- Genetic influences
- Heart Disease
- Metabolic Syndrome
- Diabetes
- Chronic medical illness
- Smoking
- Sleep problems
- Black/Latinx race/ethnicity
- Alcohol Abuse
- Depression/Anxiety

**Weaker Risk Factors**
- Female gender
- History of head injury
- Lower level of education
- Low activity level (cognitive, social, and physical)
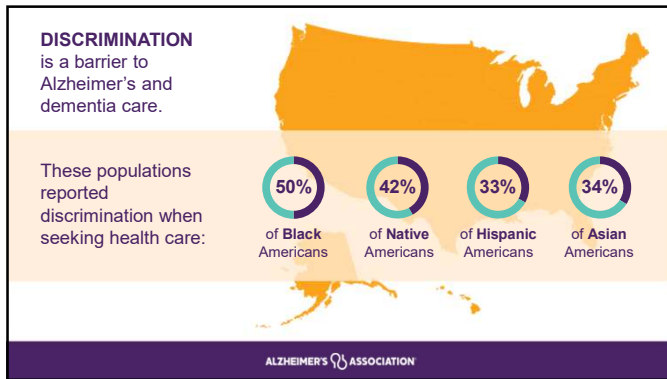- Stress

Which ones can we affect?

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## Slide 30

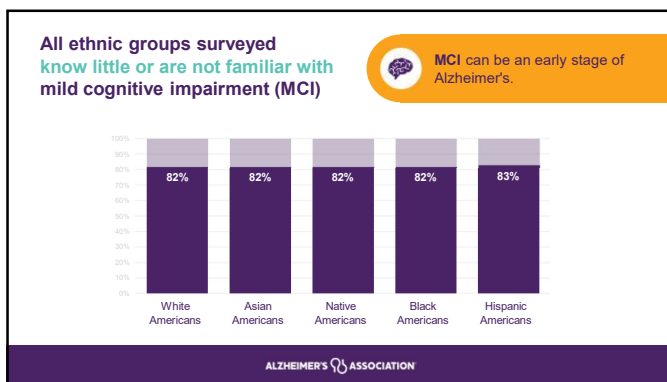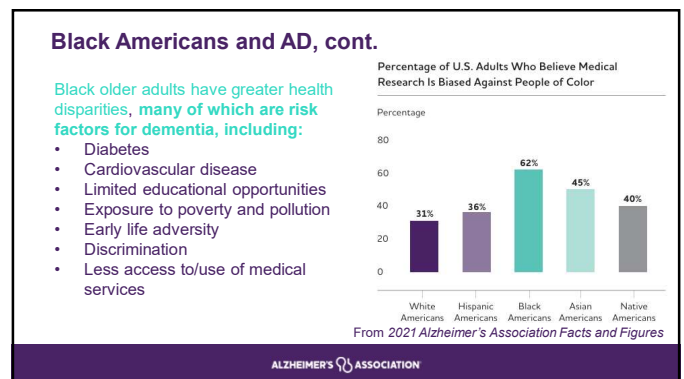# General Facts on Diverse Populations

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**DISCRIMINATION** is a barrier to Alzheimer's and dementia care.

These populations reported discrimination when seeking health care:

**50%** of **Black** Americans

**42%** of **Native** Americans

**33%** of **Hispanic** Americans

**34%** of **Asian** Americans

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**Hispanic, Black, and Asian American dementia caregivers indicate:**

Greater care demands

Less use of outside help

Greater depression

**compared to White American caregivers.**

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**All ethnic groups surveyed know little or are not familiar with mild cognitive impairment (MCI)**

**MCI** can be an early stage of Alzheimer's.

| White Americans | Asian Americans | Native Americans | Black Americans | Hispanic Americans |
|---|---|---|---|---|
| 82% | 82% | 82% | 82% | 83% |

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# Black and African Americans

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**Black Americans and Alzheimer's Disease**

Black Americans are about **2 times** as likely as White Americans to have Alzheimer's and other dementias, but they are less likely to receive a diagnosis.

**1/2** say that they have experienced discrimination while seeking care for a person living with Alzheimer's.

Black Americans are **35%** less likely to be diagnosed with dementia than white Americans and are generally diagnosed later in the disease progression, limiting access to amyloid- targeting medications.

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**Black Americans and AD, cont.**

Black older adults have greater health disparities, **many of which are risk factors for dementia, including:**

- Diabetes
- Cardiovascular disease
- Limited educational opportunities
- Exposure to poverty and pollution
- Early life adversity
- Discrimination
- Less access to/use of medical services

Percentage of U.S. Adults Who Believe Medical Research Is Biased Against People of Color

Percentage

| White Americans | Hispanic Americans | Black Americans | Asian Americans | Native Americans |
|---|---|---|---|---|
| 31% | 36% | 62% | 45% | 40% |

From *2021 Alzheimer's Association Facts and Figures*

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## Hispanic and Latino/Latina Americans

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## Hispanic Americans and Alzheimer's Disease

Hispanic Americans are about **1.5 times** as likely as White Americans to have Alzheimer's and other dementias.

**57%** believe that a significant loss of memory or cognitive abilities is a "normal part of aging."

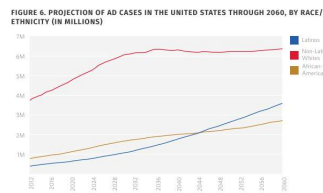**1 in 3** report that they have experienced discrimination when seeking health care.

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## Hispanic Americans and AD, cont.

Hispanic older adults have greater health disparities, **many of which are risk factors for dementia, including:**

- Diabetes
- Cardiovascular disease
- Lower income and educational obtainment
- Less access to/use of medical services

FIGURE 6. PROJECTION OF AD CASES IN THE UNITED STATES THROUGH 2060, BY RACE/ETHNICITY (IN MILLIONS)



From *Latinos & Alzheimer's Disease: New Numbers Behind the Crisis*, 2016

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## Middle Eastern/North African (MENA) Americans

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## MENA Americans and Alzheimer's Disease

Compared to other ethnic groups, MENA populations are often underrepresented in dementia research, making it difficult to accurately assess the prevalence and risk factors within this community.

The Arabic word for dementia, **"alkharaf"**, can be considered derogatory, further hindering individuals from seeking help.

Some studies indicate that foreign-born MENA women may have a significantly higher rate of undiagnosed dementia compared to MENA men

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## MENA American and AD

MENA older adults have greater health disparities, **many of which are risk factors for dementia, including:**

- Diabetes
- Cardiovascular disease
- Depression (with cultural stigma surrounding mental health treatment)
- Lower income and educational obtainment
- Less access to/use of medical services

Rates of Cognitive Impairment
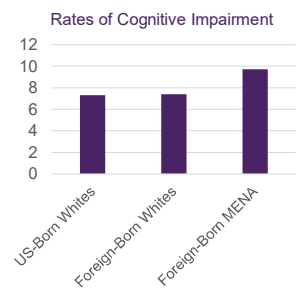


Dallo, F. J., Kindratt, T. B., & Zahodne, L. (2021). *Innovation in aging.*

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## Jewish Americans

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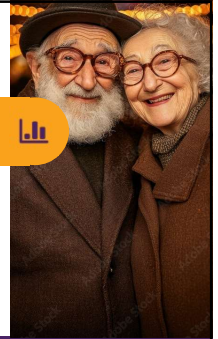## Jewish Americans and Alzheimer's Disease

The risk of developing dementia is higher for Jewish Americans due to genetic factors, especially for those with Ashkenazi Jewish Ancestry.

Non-Ashkenazi jews are more likely to develop Early Onset Dementia (before age 65) than non-jews.

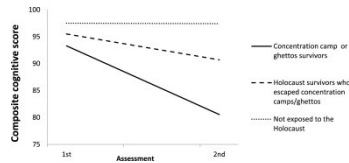Holocaust survivors are **21%** more likely to develop dementia than non-survivors.

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## Jewish Older Adults and AD and LBD

People of Ashkenazi Jewish descent are at a higher risk of developing certain types of dementia, including **Alzheimer's disease and dementia with Lewy bodies** (DLB), due to a number of factors, including:

- Genetic risk factors, including APOE and GBA, among others.
- Genetic isolation

Holocaust exposure and late-life cognitive performance in men with coronary heart disease

Concentration camp or ghettos survivors

Holocaust survivors who escaped concentration camps/ghettos

Not exposed to the Holocaust

(Weinstein et al., 2020)

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## People Living with HIV

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## People Living with HIV and Alzheimer's Disease and HAND

People living with HIV are 5x more likely to experience cognitive decline than those without HIV

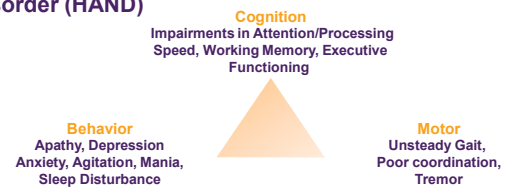**60%** of people living with HIV over the age of 50 and/or living with HIV 15+ years experience memory loss….

…but **36%** have NOT discussed this issue with a medical provider.

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## Clinical Features of HIV Associated Neurocognitive Disorder (HAND)

**Cognition**
Impairments in Attention/Processing Speed, Working Memory, Executive Functioning

**Behavior**
Apathy, Depression
Anxiety, Agitation, Mania,
Sleep Disturbance

**Motor**
Unsteady Gait,
Poor coordination,
Tremor

**Unlike MCI/ADRD:**
- Efficiency in learning and retrieval are reduced, but primary memory disturbances are rare
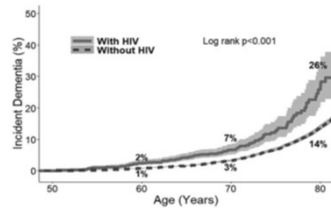- Motor symptoms often present

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## People Living with HIV and AD/HAND

People Living with HIV have higher rates of many of the **co-morbidities which are risk factors for dementia, including:**

- Diabetes
- Cardiovascular disease
- Depression and chronic stress
- Substance use disorders
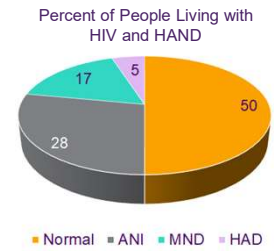- Greater number of chronic health conditions



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## Risk Factors for HAND

- Age
- Low lowest CD4 count
- Low current CD4 count
- Poorly controlled viral load
- High blood pressure
- Diabetes
- Substance use disorders
- High cholesterol
- Hepatitis C

Percent of People Living with HIV and HAND



- Normal  - ANI  - MND  - HAD

*Modified from Ellis et al., 2007 & Grant et al., 2009*

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# People who Are LGBTQ+

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## LGBTQ+ Americans and Alzheimer's Disease

LGBTQ+ individuals are **29%** more like likely to report subjective cognitive decline (a possible precursor to dementia) than their cisgender, heterosexual counterparts.

Up to **30%** delay medical care due to fear of discrimination

**40%** report that their support networks have become smaller over time.
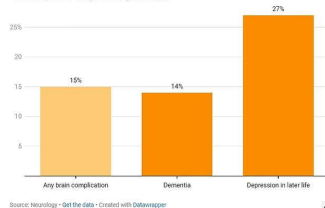
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## LGBTQ+ Americans and AD

LGBTQ+ older adults have higher rates of many of the **co-morbidities which are risk factors for dementia, including:**

- Depression
- Obesity
- Alcohol and tobacco use
- Fewer preventative screenings
- Cardiovascular disease
- HIV

**Dementia and depression in later life MORE LIKELY to strike gay, lesbian, bisexual or trans adults**

% risk compared to straight and cisgender adults



Source: Neurology • Get the data • Created with Datawrapper

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# People with Intellectual/Developmental Disabilities

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## People with Intellectual/Developmental Disabilities and Alzheimer's Disease

More than 50% of people with Down syndrome will develop Alzheimer's and individuals with other intellectual and developmental disabilities may be at increased risk for dementia as well.

People with Down Syndrome not only have a higher risk of AD, they also develop it much younger and progression is generally quicker than in those without DS.

Diagnosing dementiaa in this population is complicated by the fact that no formal neuropsychological testing has been normed in those with I/DD.

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## Individuals with I/DD and AD

Older adults with I/DDs have higher rates of many of the **co-morbidities which are risk factors for dementia, including:**

- Diabetes
- Heart disease
- Sleep Disorders
- Epilepsy
- Depression/anxiety
- Low activity level
- Lower educational obtainment

Comparison of dementia prevalence rates by age



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# Veterans

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## Veterans and Alzheimer's Disease

Veterans are at higher risk of developing dementia than non-veterans

A recent meta-analysis estimates the increase in dementia risk from any form of TBI was **70%**

Veterans with PTSD have almost **double** the dementia risk of veterans without PTSD.

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## Veterans and AD

Veterans have higher rates of many of the **co-morbidities which are risk factors for dementia, including:**

- Heart disease
- Depression
- High Cholesterol
- PTSD
- Traumatic Brain Injury
- Exposure to Agent Orange



Traumatic brain injury and risk of dementia in older veterans | Neurology

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# Thank you for Attending!

**Please scan below to complete the evaluation and receive your CMEs**

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