

# Lesbian, Gay, Bisexual, Transgender (LGBT) Dementia Care

What We Can Do to Support LGBT Adults Living with Dementia

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Part of the National Alzheimer's and Dementia Resource Center webinar series sponsored  
by the Administration for Community Living.

# Objectives

Participants in this webinar will be able to:

1. List four best practices for LGBT dementia care.
2. Discuss issues that affect LGBT older adults living with dementia and their care partners.
3. Identify seven dementia risk factors for LGBT older adults.
4. Identify LGBT dementia resources.

# Background

- San Francisco LGBT Aging Policy Taskforce released a “Policy Issues & Recommendations” report in March of 2014.
- From the report, two new LGBT/Aging programs were developed and put out for bidding. Those programs are:
  - Isolation Prevention Services for LGBT Seniors/Adults with Disabilities
  - Dementia Care Project in Service to LGBT Seniors/Adults with Disabilities



[LGBT Aging at the Golden Gate Policy Issues and Recommendations](#)

# Background

*Funded by San Francisco  
Department of Disability and Adult Services*




# 2020 Alzheimer's Disease Facts and Figures



 **6th** Alzheimer's disease is the leading cause of death in the United States

Between 2000 and 2018 deaths from heart disease have decreased **7.8%** ↓ while deaths from Alzheimer's disease have increased **146%** ↑

More than **5 million** Americans are living with Alzheimer's

An icon representing a group of people, consisting of several stylized human figures in a pyramid-like arrangement.

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

It kills more than breast cancer and prostate cancer combined

 **16 million** Americans provide unpaid care for people with Alzheimer's or other dementias

An icon showing a hand holding a stylized human figure, symbolizing care or support.

# LGBT & Dementia

- We know very little about Alzheimer's disease and dementia in the LGBT community.
- A recent study (Flatt, 2019) surveying 3,165 LGBT and 106,906 non-LGBT adults aged 45+ across 24 states from 2015-2017 showed that
  - **1 in 6 LGBT adults** (15.7%) reported subjective cognitive decline compared to 1 in 10 non-LGBT adults (10.5%).
  - Additional challenges for LGBT individuals:
    - More likely to report **giving up day-to-day activities** (61% vs. 48%)
    - More likely to report **needing help with household tasks** (46% vs. 37%)
    - **Interfered** with social activities, work, or volunteering (48% vs. 35%)

# LGBT Dementia Care Training

## Two training modules:

- Tier 1: LGBT Dementia Care (3 hours)
  - Overview of dementia, LGBT prevalence and risk factors.
  - Understanding LGBT People with Dementia (e.g., functioning, limitations, barriers to care).
  - Better practices for working with LGBT people with dementia and LGBT caregivers.
- Tier 2: Effective Communication Strategies (90 minutes)
  - Communication changes throughout the course of the dementia.
  - Identify strategies to decode and respond to the verbal and behavioral messages delivered by LGBT individuals with dementia.

# LGBT Dementia Care Training

## Training participants:

- Healthcare and social service providers in San Francisco

## Where the trainings are provided:

- At the requesting organization's site
- Public library or any community-based organizations that are willing to share their spaces (if trainings are open to the public)
- Training request: Please contact Arthur Chan, [archan@alz.org](mailto:archan@alz.org).



# LGBT Dementia Care Training

## Trainers

### Alzheimer's Association:

- Arthur Chan
- Edie Yau
- Alex Morris

### Family Caregiver Alliance:

- Christina Irving
- Adriana Sanchez

### Openhouse:

- Rochelle Towers
- Beck Epstien

# Introductions

What is your name and gender pronoun?

What is your role in your organization?

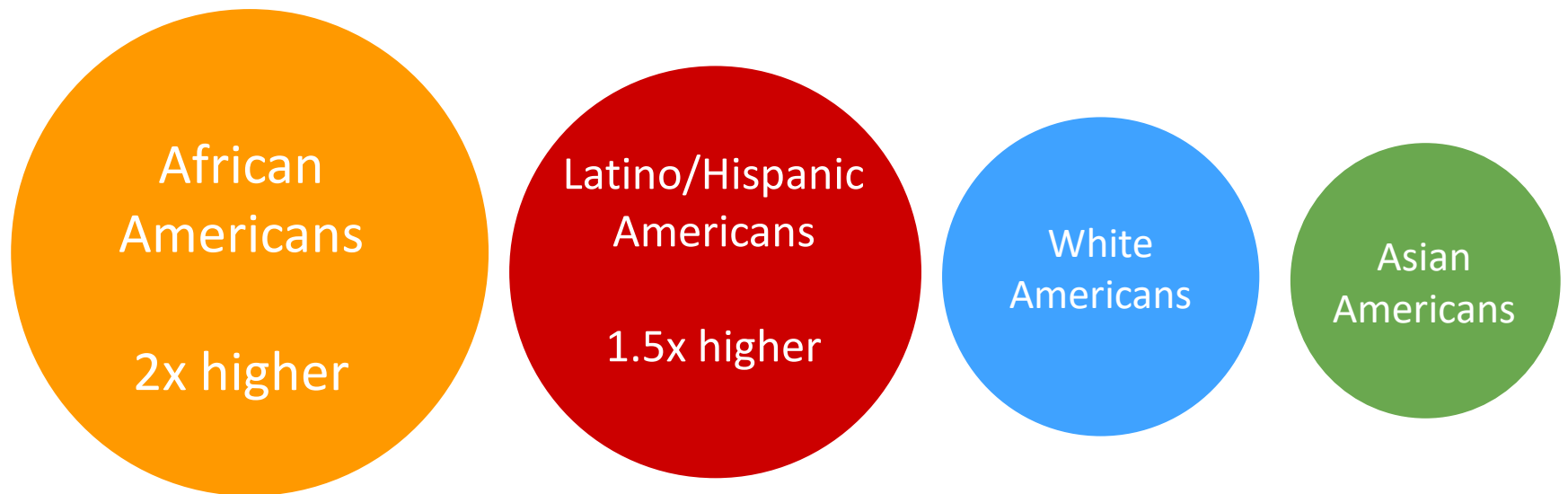


# Timeline

Events	Age		
	Maria, 89	Jose, 68	Sarah, 45
Lavender Scare: LGBTQ banned from federal government (1953)	22	1	--
Sir Lady Java challenges Rule 9, leading to legalization of cross-dressing (1967)	36	15	--
Stonewall Riots against police violence (1969)	38	17	--
Homosexuality removed from DSM (1973)	42	21	--
Harvey Milk elected (1977)	46	25	2
FDA approves HAART treatment for HIV/AIDS (1995)	64	43	20
Don't Ask Don't Tell repealed (2011)	80	59	36
SCOTUS: Marriage Equality (2015)	84	63	40

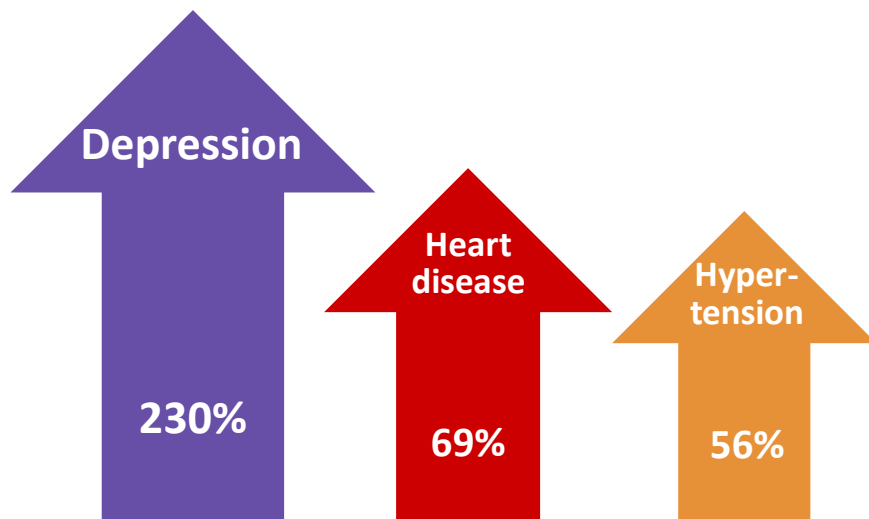
# Prevalence of Dementia

By race and ethnicity



# LGBT Risk Factors

LGBT seniors were more likely to have dementia if they also had...



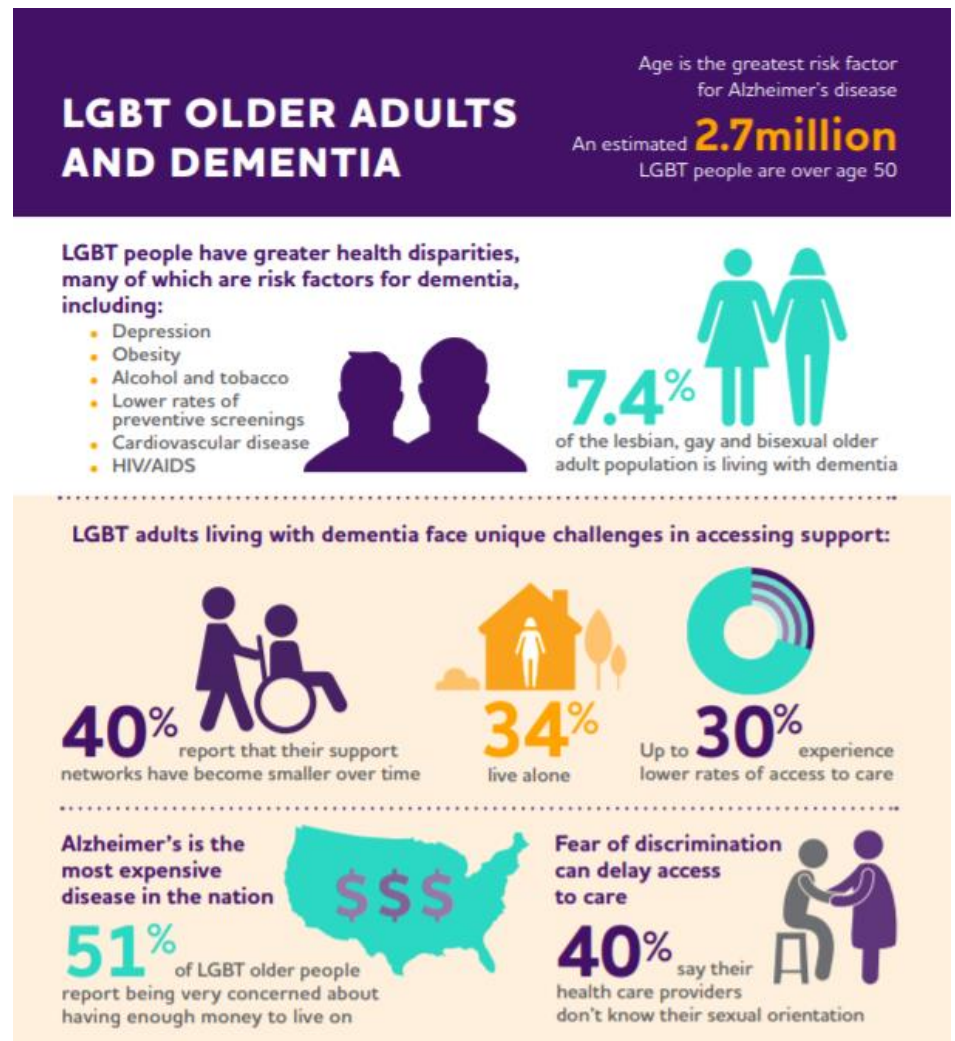
Compared to the general population LGBT community has higher rates of:



# Health Disparities

- LGBT older adults are 2x more likely to remain single
- 2x as likely to live alone
- 3-4x less likely to have children to support them

[LGBT Older Adults and Dementia Fact Sheet](#)



# What Can Organizations do?

1. Educate your staff on LGBT cultural competency.
2. Expand your definition of family.
3. Use LGBT-affirming language.
4. Engage in LGBT-specific outreach.
5. Incorporate LGBT people into your marketing materials.
6. Find or create support groups specifically for LGBT caregivers living with dementia.
7. Partner with local LGBT community groups.
8. Advocate for nondiscrimination protections.
9. Collect information on sexual orientation and gender identity.





Caring for someone with Alzheimer's isn't easy.  
Reaching us is.



If you care for someone with Alzheimer's disease, memory loss or dementia, you are not alone. We're here day or night — whenever you need us — offering reliable information and support.

Free 24/7 Helpline: **800.272.3900**  
LGBT Dementia Care Network: [alz.org/norcal](http://alz.org/norcal)

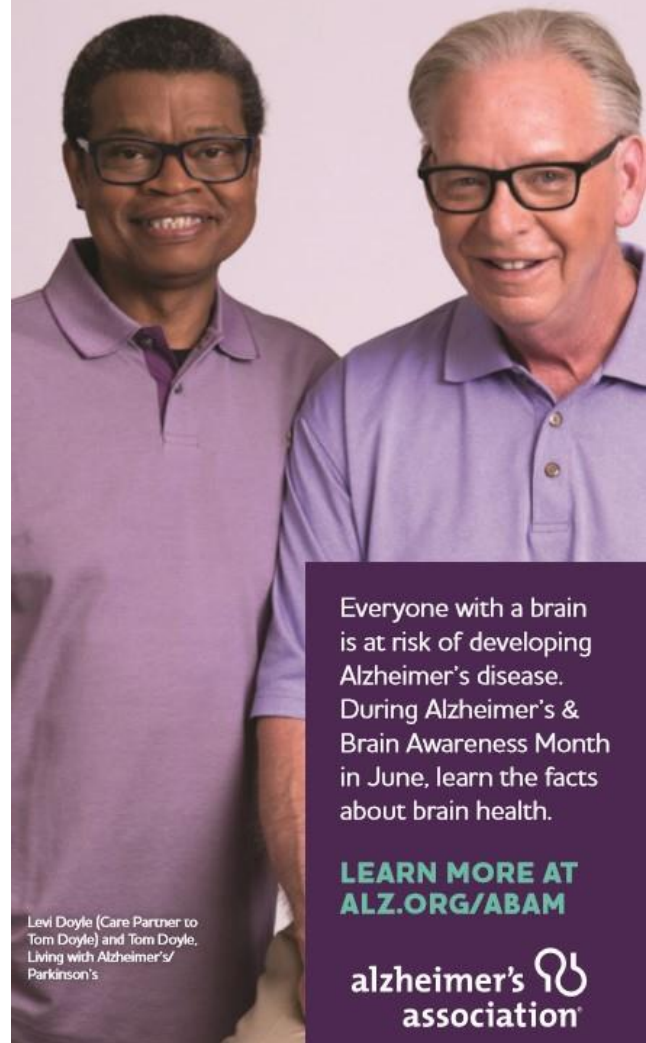
alzheimer's   
association

# TAKE PRIDE IN YOUR BRAIN



Steven Krzanowski, Alzheimer's Association Events Manager (left) and Jaime McElmon, RN at Sutter Health and Alzheimer's Association Volunteer (right)

# TAKE PRIDE IN YOUR BRAIN



Everyone with a brain is at risk of developing Alzheimer's disease. During Alzheimer's & Brain Awareness Month in June, learn the facts about brain health.

**LEARN MORE AT**  
[ALZ.ORG/ABAM](http://ALZ.ORG/ABAM)

Levi Doyle (Care Partner to Tom Doyle) and Tom Doyle, Living with Alzheimer's/Parkinson's

alzheimer's   
association



# What Can Individuals Do?

## Nonverbal behavior

- Attention to facial expression and body language

## Emotional connection

- Respond to the feelings rather than the words or content
- Respond calmly to anger and other negative emotions
- Reassure, reassure

## Dignity and integrity

- Acknowledge strengths
- Do not talk down to the person (no baby talk)

## Evaluate and reevaluate

- Grounding self first
- Mood check
- Body scan
- Re-ground in your intention

### LGBT considerations

- Word that someone used (e.g., queer, homosexual)
- Clothing people have been dressed in
- Importance of connecting with people in their life
- Knowing their history

# Training Outcomes in Three Years

- Developed curriculum
- **81** trainings
- **175 hours** of training
- **1500 staff and volunteers** trained
- Also offered in Chinese and Spanish
  
- Dementia Summit
- Dementia Care Network Conversation



# Training Impact

A conversation with Mr. Charles Symes,  
Founder & CEO, Alegre Home Care

# LGBT Resources

- [LGBT Dementia Issues Brief](#)
- [LGBT Older Adults and Dementia Infographic](#)
- [Recommendations for Supporting LGBT People Living with Dementia](#)
- [LGBT Caregiver Concerns brochure](#)
- [LGBT Community and Allies online forum](#)

[Issues Brief on LGBT Dementia](#)

[Recommendations for Supporting LGBT People](#)

Questions?