

## San Francisco LGBT Aging Policy Task Force

### Issues Related to LGBT Older Adults and the Risk of Alzheimer's Disease and Other Forms of Dementia

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"San Francisco is facing a growing crisis in dementia care. Age is the strongest risk factor for the development of dementia. Seniors make up a higher proportion of the city's population (17.6% at the time of the 2000 Census) than they do statewide or nationally (14% and 16.5% nationally). In the Bay Area, one out of every three people 85+ has some type of dementia. Between now and 2020, San Francisco will experience a dramatic increase in the number of its citizens with Alzheimer's or other dementing illnesses. Between 2010 (the baseline year) and 2030 there will be a 49% increase in the number of people with Alzheimer's related dementias (from 23,445 to 34,837). This does not include the number of people with other forms of dementia and mild cognitive impairment (MCI)". \*

\* From: *San Francisco's Strategy for Excellence in Dementia Care*, December, 2009

Dementia is an acquired, persistent, intellectual impairment involving multiple cognitive domains, such as:

- memory*, usually the ability to remember events, facts, people or locations that were experienced recently;
- executive function*, which includes the ability to think abstractly, make sound judgments and plan and carry out complex tasks;
- language*, such as the ability to generate coherent speech or understand spoken or written language;
- visuospatial function*, or the ability to recognize or identify objects, people or places or to navigate through well known locations; and
- behavior*, such as lack of motivation, depression, hallucinations, delusions or personality changes.

Impairments in these cognitive abilities must be severe enough to cause a decline in an individual's day-to-day function, such as performing duties necessary for work, household chores or even self-care. Dementia can be caused by a variety of diseases and conditions that result in dysfunction and damage to brain cells. At the end of this Case Statement is an explanation of the stages and types of dementia.

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## LGBT Issues Related to Alzheimer's and Other Forms of Dementia

Based on several surveys, including the LGBT Aging Policy Task Force survey, Fredrikson-Goldsen, et. al. 2013, we can extrapolate, using the city's demographic projections, how dementia may impact the LGBT older adult community in San Francisco. Using a 12% estimate for the total LGBT population in the San Francisco (probably low), we can assume the following:

In 2020, the total population of older adults in San Francisco living with Alzheimer's = 26,774

A breakdown by age group - with estimates of the LGBT senior population with Alzheimer's is as follows:

Age 65-74:	2.75% of the total population (81,725) = 2,247 LGBT = 270 (12%)
Age 75-84:	26% of the total population (42,017) = 10,924 LGBT = 1,311 (12%)
Age 85:	57% of the total population (23,865) = 13,603 LGBT = 1,632 (12%)

In 2030, the total population of older adults in San Francisco living with Alzheimer's = 34,837

A breakdown by age group - with estimates of the LGBT senior population with Alzheimer's is as follows:

Age 65-74:	2.75% of the total population (89,239) = 2,427 LGBT = 291 (12%)
Age 75-84:	26% of the total population (63,025) = 16,387 LGBT = 1,966 (12%)
Age 85:	57% of the total population (28,111) = 16,023 LGBT = 1,922 (12%)

The estimates above are specifically for Alzheimer's disease. The Alzheimer's Association estimates that Alzheimer's accounts for approximately 60% of all dementias. Accordingly these estimates may be low in regard to the total number of LGBT older adults in San Francisco with all forms of dementia, due in part to the prevalence of AIDS-related dementia. Below are two charts that show what the total dementia estimates are for 2020 and 2030 for the LGBT senior population.

2020	LGBT Senior Population with all forms of Dementia		Total 2020 LGBT Dementia Estimate
	Alzheimer's Disease (60%)	Other Dementias (40%)	
Age 65-74:	270	180	450
Age 75-84:	1,311	874	2,185
Age 85:	1,632	1,088	<u>2,720</u>
			<b>5,355</b>

2030	LGBT Senior Population with all forms of Dementia		Total 2030 LGBT Dementia Estimate
	Alzheimer's Disease (60%)	Other Dementias (40%)	
Age 65-74:	291	194	485
Age 75-84:	1,966	1310	3,276
Age 85:	1,922	1281	<u>3,203</u>
			<b>6,964</b>

It has been well documented that LGBT seniors are reluctant to access long term services and supports (Fredriksen-Goldsen et. el, 2013, Jensen, 2012, Adelman, et. al., 2006). LGBT seniors, 70 years of age or older, grew up and became adults in the pre-liberation era when disclosure invariably meant rejection, loss and possibly incarceration. Consequently, LGBT seniors often fear for their safety if they invite service providers into their lives and their homes. LGBT seniors often go back into the closet to access needed services or at the risk of jeopardizing their health and well being do not access these services at all.

“One of the biggest challenge LGBT seniors and their caregivers have is access to support services. LGBT seniors with dementia as well as their caregivers are reluctant to access support services in San Francisco. Fear of discrimination keeps these seniors from coming out in our ( Alzheimer Association) support groups. The older the LGBT person is, between 65 to 90, the less likely they are to be out in our groups. There are 2,200 to 2,700 participants in our support groups, approximately 700 to 800 people on a month. Approximately 2 to 5 % of support group participants may be LGBT at any one time but the percent out is smaller than that. Level of outness, who they are comfortable being out with, is what makes the difference” (Heather Gray, Heather Gray, Alzheimer's Association Northern California-Northern Nevada, Family Support Coordinator.

“There is a level of mistrust of service and service providers. LGBT seniors and their caregivers are often fearful of people coming into their world”... Erica Erney, LCSW, Volunteer Facilitator, LGBT dementia caregiver support group, Alzheimer Association and Openhouse. This mistrust is not entirely misplaced. Few dementia care providers or caregiver support groups are LGBT welcoming and sensitive. More LGBT sensitive service providers, group facilitators and materials would assist seniors to feel more welcome and more trusting that it is safe to be “out”.

Discrimination, fear of discrimination and living alone increases the risk of isolation in LGBT seniors and are barriers to securing appropriate care and services. These factors are compounded when a person is challenged by a chronic illness. This is especially true for persons with Alzheimer/dementia. “Unlike other illnesses, the person with dementia cannot be the individual asking for help. If you don't have a plan in place, you can easily be in trouble and become isolated.” (Janice Wallace, Elder Coach, small business owner).

According to Edie Yau, Director of Diversity & Inclusion, Alzheimer's Association Northern California and Northern Nevada Chapter, “While discrimination is a real problem, there's a larger problem of not knowing where to go for dementia services”. The LGBT community remains largely uninformed about the disease and the resources and supports available to help people manage daily tasks as the disease progresses.

Mainstream seniors rely on the assistance of a spouse, adult children, and other family members to research disease information and to access long term services and supports. But studies have found that San Francisco LGBT seniors are significantly more likely than heterosexual seniors to be childless, single, and live alone ( Karen Fredrikson- Goldsen et. al, 2013, Diana Jensen, 2012, Adelman et. al, 2006). These factors have important implications for care and support for LGBT seniors since having children and/or a partner reduces the likelihood of poverty, and increases access to information, services and care in old age.

LGBT seniors rely on their family of choice for support and assistance. But families of choice are more often than not people of similar age and so are aging at the same time. Friends may well need services themselves when a senior is in need of assistance. Further, families of choice exist outside of legal support and are challenged by legal obstacles when providing care. Clearly LGBT seniors are in need of more formal support systems to assist them in accessing needed care.

Future planning, correct information about Alzheimer and where to go for LGBT sensitive dementia services are all critically important issues that will need to be addressed if LGBT older adults and seniors with Alzheimer/dementia are to live as long as possible and as well as possible in their homes and in their own communities.

#### Major Issues:

- Isolation
- History of discrimination, discrimination, and fear of discrimination
- Dual Stigma - LGBT & dementia
- Lack of family support
- Lack of informal caregiver support
- Lack of information about dementia
- Denial
- Complications from HIV/AIDS
- Lack of advanced care planning

#### Potential Recommendations to Health and Human Services Subcommittee:

1. Create an LGBT targeted education and awareness campaign about dementia and the issues it presents to LGBT persons. This would include topics and information on:
  - Risk reduction
  - Early identification of dementia
  - What to expect as the disease progresses
  - Services and resources
  - Caregiver wellness and support
  - Disease management for mild, moderate & advanced dementia, including end of life
  - Advanced care planning
  - Ethical issues
  - Emergency preparedness and safety.

2. Create an informational campaign about the importance of advanced care planning, including:
  - What is advanced care planning (ACP)
  - Why is it especially important that people with dementia engage in ACP
  - Who should be involved in the ACP process and why
  - What specific issues should be covered during ACP:
    - Identification of a surrogate or decision-maker
    - Preferences regarding life support and CPR
    - Hospice and palliative care
  - What steps are involved in ACP
  - What is POLST (physician order for life sustaining treatment)
  - Code status while in hospital
3. Work to create new and strengthen existing LGBT-specific dementia caregiver services.
  - Create a coalition of LGBT organizations that provide services to LGBT older adults, e.g. Openhouse, Shanti, Maitri, Lyon-Martin, Black Coalition on AIDS, Lesbian Health Resource Center, etc. This would reduce the risk of service duplication, increase cost-effectiveness, and create the widest possible outreach to diverse LGBT communities.
4. Create cultural competency/dementia capable training. .
  - Encourage (Mandate) LGBT sensitive senior/dementia capable training for all city departments and vendors delivering direct services to LGBT seniors.
  - Develop an LGBT sensitive/dementia capable training module for senior care facilities, such as independent and assisted senior housing, nursing homes, adult day health and dementia programs
  - Create cultural competency training for first responders tailored to LGBT seniors living with dementia and their caregivers

All of these recommendations should be explored and implemented, when possible, in collaboration with the Alzheimer's Association of Northern California and Northern Nevada and the Department of Adult Aging Services.

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K. Fredriksen-Goldsen, H. Kim, C. Hoy\_Ellis, J. Goldsen, D. Jensen, M. Adelman, L.M. Costa, B. DeVries, *Addressing the Needs of LGBT Older Adults in San Francisco*, 2013.

D. Jensen, *Lesbian, Gay, Bisexual, Transgender Seniors in San Francisco: Current Estimates of Population Size, Service Needs and Service Utilization*, 2012.

M. Adelman, J. Gurevitch, B. DeVries, & Blando, J. (2006). "openhouse: Community Building and Research in the LGBT Aging Population." In D. Kimmel and S. David, (Eds.), *Research and Clinical Perspective on Lesbian, Gay, Bisexual and Transgender Aging*. New York: Columbia University Press.

## ATTACHMENT I

### **Stages of Dementia:**

Although advancing age is recognized as the strongest risk factor for developing dementia, **Early (Younger) Onset** forms of dementia are increasingly being recognized and can be particularly devastating as they affect individuals at the height of their careers or when they have caregiving responsibilities for young children or elderly parents. The term younger-onset refers to dementia that occurs in a person who is under age 65 when symptoms begin. People who have younger-onset dementia may be in any stage of dementia – early, middle or late. Experts estimate approximately 500,000 Americans in their 30s, 40s and 50s has Alzheimer's disease or another dementia. In this age group, a different dementia called frontotemporal dementia is as common as Alzheimer's.

All forms of dementia advance in stages. While the exact progression and symptoms vary depending upon the form of dementia, the stages are generally characterized as moving from very early (or MCI) to mild to moderate to advanced or late stages.

**Mild Cognitive Impairment (MCI)** is a less severe or very early stage of illnesses which can cause dementia. Individuals with MCI have an acquired intellectual impairment that is *NOT* sufficient to cause a decline in function, for which an individual can compensate. Some people with MCI go on to develop dementia, but many do not. Because some causes of dementia are reversible, MCI represents a window of opportunity during which interventions that stall or prevent the onset dementia may be initiated.

A person with MCI may have problems with memory, language or another essential cognitive function that are severe enough to be noticeable to others and show up on tests, but not severe enough to interfere with daily life. A common form of MCI is characterized by short-term memory problems, but few other symptoms of dementia (e.g., problems with language, judgment, changes in personality or behavior) that impair a person's daily functioning.

**Stages of dementia.** Experts have documented common patterns of symptom progression that occur in many people with Alzheimer's and have developed several methods of "staging" based on these patterns. Staging provide a useful frame of reference for understanding how the disease may unfold and for making future plans. But it is important to be aware that not everyone will experience the same symptoms or progress at the same rate. People with Alzheimer's die an average of four to six years after diagnosis, but the duration of the disease can vary from three to 20 years.

People with non-Alzheimer's dementias will progress differently and may not adhere to stages in the same way as people with Alzheimer's might. However, all dementia diseases are progressive and people will continue to be impacted by the disease, even though they may transiently stabilize in the course of any of these diseases. It is hoped that with the development of new treatments, some of the symptoms, or even progression of the disease may be altered or arrested.

The stages below apply specifically to what is recognized for people with Alzheimer's disease.

**Early Stage:** Early-stage is the part of Alzheimer's when problems with memory, thinking and concentration may begin to appear in a doctor's interview or medical tests. People in the early-stage typically need assistance with simple daily routines. At the time of a diagnosis, an individual is not necessarily in the early stage of the disease; he or she may have progressed beyond the early stage.

**Moderate or mid-stage Alzheimer's:** Gaps in memory and thinking are noticeable, and individuals begin to need help with day-to-day activities. At this stage, those with Alzheimer's may be unable to recall their own address or phone number or the high school or college from which they graduated; become confused about where they are or what day it is; have trouble with less challenging mental arithmetic; need help choosing proper clothing; still remember significant details about themselves and their family and still require no assistance eating or using the toilet.

**Moderately severe Alzheimer's:** Memory continues to worsen, personality changes may take place and individuals need significant help with daily activities. The person may: lose awareness of recent experiences as well as their surroundings; remember their own name but have difficulty with their personal history; distinguish familiar and unfamiliar faces but have trouble remembering the name of a spouse or caregiver; need help dressing properly; experience major changes in their sleep patterns; need help handling details of the toilet;



have increasingly frequent trouble controlling their bladder or bowels; experience major personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior; and tend to wander or become lost.

**Severe, or late-stage Alzheimer's:** In the final stage of this disease, individuals lose the ability to respond to the environment, to carry on a conversation and, eventually, to control movement. At this stage, individuals need help with much of their daily personal care, including eating or using the toilet. They may also lose the ability to smile, to sit without support and to hold their heads up. Reflexes become abnormal, muscles grow rigid and swallowing is impaired.

### Types of Dementia:

There are many other causes of dementia other than Alzheimer's. These include the following:

- Vascular dementia (also known as multi-infarct dementia) is the second most common form of dementia; individuals often experience sudden deterioration, which may progress over time.
- Parkinson's disease and related disorders, in which individuals develop severe problems of movement and balance, sometimes including cognitive and behavioral impairments.
- Huntington's disease, a hereditary disease often appearing in early adulthood, passed on from parent to child, the symptoms of which include quick jerky movements of the face, limbs, and trunk, cognitive and psychiatric impairments.
- Dementias associated with physical disorders such as diabetes, thyroid disease, brain tumors, or Acquired Immune Deficiency Syndrome (AIDS).
- Dementias related to alcohol or substance abuse; these may be a combination of direct chemical damage to the brain combined with nutritional or vitamin deficiencies.

San Francisco's Strategy For Excellence in Dementia Care, Alzheimer's Dementia Expert Panel for Department of Aging and Adult Services, December 2009

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## ATTACHMENT II

### Interviews

#### **Doris Bersing, Ph.D. In-home senior service provider and small business owner**

When assisting a person with dementia, it is important to remember there is a person there. Someone who may or may not have acquired wisdom, someone who may or may not have been self-aware, someone who lived their life one way but because of dementia is now expressing themselves in another way. People who were always angry in their life may now become very sweet and calm. Previously calm people may become agitated and angry. Sexual orientation may also shift in unexpected ways. Someone who had been gay, may become attracted to the opposite sex. Someone who is heterosexual may start flirting with same sex people. In late stage, people will not recognize their partner or spouse. All these changes create challenges for partners/spouses, family and friends. The community needs to be educated about dementia. The more educated we are, the more compassion and support we can give ourselves and each other.

Not all dementias are alike. With Korsikoff, an alcohol abuse related dementia, the person is still cohesive but the person will confabulate and become paranoid and confused. These symptoms make care very challenging. I have seen lesbians with Korsikoff. Back in the 1960's, bars were often the center of the community. Many gay men and lesbians became alcoholics. I think because of the history and social experience with alcohol we may see more alcohol related dementia.

I worked 12 years as a trainer in senior facilities. I found that training educated the facility owners, nurses and staff but in the end they only learned to tolerate us. We need to find a better model of teaching that gets to the core of homophobia and discrimination. We need to do more than just show what good human beings we are, we have to help people feel in their gut what it feels to be discriminated.

#### Recommendations:

There are no two people alike. There are no two people with dementia alike. One size doesn't fit all. We need to have general guidelines and training that understand this. If we are to provide good care we must make an individual assessment of that person's needs and not just assume that because someone is straight or gay that the intervention be predefined. You need to meet the people where they are.

## **Heather Gray, Alzheimer's Association Northern California-Northern Nevada, Family Support Coordinator.**

One of the biggest challenge LGBT seniors and their caregivers have is **access** to support services.

LGBT seniors and their caregivers are more likely to participate in support groups that are in LGBT friendly or neutral space. Churches are not perceived as friendly or neutral space.

Hospitals and

senior agencies are perceived as neutral. LGBT organizations are of course considered LGBT

friendly but not all LGBT people are not out and would be comfortable in such an identified space.

Fear of discrimination keeps people from coming out in our support groups. The older the LGBT person is, say 65 years of age to 90, the less likely they are to be out in our groups. There are approximately 2200 to 2700 participants in our support groups, approximately 700 to 800 people on a month. I would guess approximately 2 to 5 % of support group participants may be LGBT at any one time but the percent out is smaller than that. Level of "outness", who they are comfortable being out with is what makes the difference.

All support groups are walk-in and open to the public. No questions are asked about sexual orientation or gender. However, if someone contacts the HelpLine referral they will be asked about sexual orientation.

There is definitely a need for support groups. But the level of outness deters people People aren't accessing services for fear of discrimination. They may be out in some part of their world but not in others where they feel more vulnerable.

### Recommendations:

1. Educate the LGBT community about Alzheimer's. It isn't normal aging. It is a disease.
2. Make resources more available. Need to do outreach.
3. Biggest challenge is this level of outness. Help people feel more comfortable and safe.

**Erica Erney, LCSW, Alzheimer's Association & Openhouse, Volunteer Facilitator, LGBT Caregiver Support Group**

Challenges: There is a level of mistrust of service and service providers. LGBT seniors and their caregivers are often fearful of people coming into their world. This fear is fear of being on the radar--- that they will be judged by social services. They are fearful that their situation will be misperceived and that someone will call Adult Protective Services and they will be separated from their partner. They fear they or their partner will be abused in assisted living facilities and nursing homes.

Accessibility -- need to have more LGBT friendly locations.

Recommendations:

1. LGBT community needs to be educated about the disease, the stages of Alzheimer and how to best plan and prepare.
2. Mainstream providers need to be educated about LGBT seniors.
3. A general educational program that reaches all people to reduce the stigma of having dementia and to create a more positive environment for people with Alzheimer and their loved ones.
4. Increase access by creating programs that have simultaneous services for both the caregiver and person living with dementia. This would give the caregiver a break from care giving without having to find someone to be at home.

**Janice Wallace, Elder Coach, Specialist in Dementia Care, Owner small business**

Challenges:

Outness. There are often old wounds around coming out that complicate care. Perhaps your being LGBT has never been accepted by your parents. If you are not partnered, you are most likely the person in your family to be asked to step up and take care of aging parents. And if you are partnered and don't have children you are again perceived by family as the

adult child most likely to step up and care for parents. But you may find yourself in a situation where your partner has never been accepted by the parent you are now taking care of. You are now being asked to spend a significant amount of your resources (including your partner) to take care of an ailing parent. The issue of resources is huge. There is a huge financial and emotional impact on the caregiver.

Isolation. Couples may become isolated. Some friends will fade away and disappear, uncomfortable being around someone who is cognitively challenged. This happens to both LGBT and heterosexual couples. But gay couples are more likely to be estranged from family, to not have children and to be more dependent on their extended network of friends.

As the partner with dementia requires more supervision, the other partner may have less time for socializing and continuing connections to friends. You start out as a team but then transition to the loss of the partnership as the disease progresses. Both people in the couple struggle with loss. The challenge of dealing with loss can also result in withdrawal and isolation.

Unlike other illnesses the person with dementia cannot be the individual asking for help. If you don't have a plan in place, you can easily be in trouble and become isolated.

#### Recommendations:

1. People need to be proactive. Get in front of this. Find out about resources before you need them. Have conversations with health care advocates and make sure they understand what you want.
2. It is easy to be overwhelmed. It helps to have a structure to follow and tools to help you get organized. Plan with friends and support each other.

### **Lou B. , Alzheimer's Association Volunteer, gay man with early stage Alzheimer's disease**

Symptoms of Alzheimer's disease appeared in late 40's/ early 50's. Symptoms got worse. Medications didn't work. He took leave from his employment. His partner needed to work. This was a huge challenge at first. I almost gave up. Need to go to one place or another. No one stop shopping. Need medical documentation. Applied for Social Security disability. Hard to gather all the forms. Couldn't drive. No bus. Transportation expensive.

Hard to find a therapist that specializes in dementia. No one in practice doing early stage. Most support groups during the day. I was working at the beginning of my diagnosis.

(Norman, his partner, continues to work.) Norman was going to a support group but decided to stop. Uncomfortable with a mixed straight and gay group. He was the only gay person in the group.

The group was accepting but asked too many questions about the lifestyle. Made Norman uncomfortable. He would prefer to have LGBT specific caregiver group.

Norman's Mother had Alzheimer's. He is a little bit older than me (6 years). I always said I would take care of him. He does my medications now. Pays the bills. Unexpected burden. A little resentment, we talk about it.

Care companion comes two times a week for three hours. She drives me places. Good not to depend on Norman all the time.

Norm helped me take care of my DAD before I got sick. They were best buddies. Both enjoyed baseball. I don't. I'm close with his Mom. I'm only child. Mom passed away in 2003. (After Lou became ill) I couldn't take care of him at home. Senior assisted place better care. He was very understanding.

I'm most concerned about the legal issues. We are domestic partners but it is murky water in terms of wills and trust. What is it going to be like if one or both of us have to go into assisted living and dementia care? How are we going to be treated as a couple? How much legal standing does Norman have to advocate for me and who will advocate for us?