

## Residents' Rights and the LGBT Community: Know YOUR Rights as a Nursing Home Resident

The federal 1987 Nursing Home Reform Law requires nursing homes to “protect and promote the rights of each resident” emphasizing individual dignity and self-determination in the provision of long-term care. Every nursing home accepting Medicare and/or Medicaid must meet federal requirements, including those regarding residents’ rights.

### Lesbian, Gay, Bisexual or Transgender (LGBT) Older Adults and Long-Term Care

Current estimates state that 9 million Americans identify as lesbian, gay, bisexual or transgender (LGBT).<sup>1</sup> One study found that 27% of LGBT baby boomers had significant concerns about discrimination as they age and there are reports that LGBT older adults encounter violations of their rights when seeking long-term care services and supports.<sup>2</sup> Incidents of abuse are often unreported or unidentified; however, a majority of individuals responding to a recent survey (578 of the 649 respondents or 89%) felt that staff would discriminate against an LGBT elder who was out of the closet.<sup>3</sup> Additionally, negative treatment, including verbal and physical harassment, by other residents was the most commonly reported problem by respondents in this study.<sup>4</sup>

Two friends of mine, Vera and Zayda, had been together for 58 years. When Vera’s Alzheimer’s became too much, Zayda moved her to an assisted living facility. Zayda could barely trust family or neighbors with the truth, let alone strangers, so she and Vera became “sisters.” Much later, after Vera’s death, Zayda needed to move into an assisted living facility herself. She had many, many photos of the love of her life, but dared not display them in her new home. The other residents would talk about husbands, children and grandchildren, but she felt too vulnerable to tell the truth. Zayda was in hiding and terribly isolated. —*Nina L., Carlsbad, CA* (LGBT Older Adults in Long-Term Care Facilities: Stories from the Field. [www.lgbtlongtermcare.org](http://www.lgbtlongtermcare.org))

### KNOW Your Rights<sup>5</sup>

Individuals living in nursing homes have the same rights to be free from discrimination and harassment as individuals living in the larger community. In addition, they have rights and protections provided by federal nursing home regulations and state and federal anti-discrimination provisions. The rights of all residents should be honored and respected, regardless of sexual orientation or gender identity or expression. Understanding your rights, learning about ways to solve problems, and knowing how to get help if issues arise is the first step in ensuring quality care. The federal nursing home regulations provide the following resident rights and facility requirements that may be of particular importance to lesbian, gay, bisexual or transgender individuals living in a nursing home. State nursing home regulations and various anti-discrimination laws may provide additional protections (see “Resources” section for link to federal nursing home regulations):<sup>6</sup>

<sup>1</sup> Gates, G. (2011) *How many people are lesbian, gay, bisexual, and transgender?* Williams Institute: UCLA School of Law. <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Gates-How-Many-People-LGBT-Apr-2011.pdf>

<sup>2</sup> MetLife Mature Market Institute, Lesbian and Gay Aging Issues Network (ASA), & Zogby International. (2006). *Out and Aging: The MetLife Study of Lesbian and Gay Baby Boomers*. MetLife. <http://www.metlife.com/assets/cao/mmi/publications/studies/mmi-out-aging-lesbian-gayretirement.pdf>

<sup>3</sup> National Senior Citizens Law Center in collaboration with Lambda Legal, National Center for Lesbian Rights, National Center for Transgender Equality, National Gay and Lesbian Task Force and Services & Advocacy for GLBT Elders (SAGE). *LGBT Older Adults in Long-Term Care Facilities: Stories From the Field*. April 2011. <http://www.lgbtagingcenter.org/resources/resource.cfm?r=54>

<sup>4</sup> *LGBT Older Adults in Long-Term Care Facilities: Stories From the Field*, loc. cit.

<sup>5</sup> For more fact sheets and additional resources regarding residents’ rights and advocating for quality long-term care visit the National Consumer Voice for Quality Long-Term Care (Consumer Voice) website [www.theconsumervoice.org](http://www.theconsumervoice.org).

<sup>6</sup> See 42 CFR 483.10 for complete list of federal nursing home residents’ rights <http://www.ecfr.gov/cgi-bin/text-idx?c=ecfr&SID=e5d3af40a300a1dbbea73a7392115694&rgn=div8&view=text&node=42:5.0.1.1.2.2.7.3&idno=42>.

## **Right to be FREE from ABUSE**

All residents have the right to be free from abuse (by any individual - including other residents) and facilities must develop and implement policies and procedures that prohibit mistreatment of residents and investigate and report allegations of abuse. Resident mistreatment includes all types of abuse; such as verbal, sexual, mental and physical abuse, neglect and financial exploitation. For example, facility staff cannot refuse to provide care due to a resident's sexual orientation nor can staff harass a resident due to his/her gender identity.

## **Right to PRIVACY**

Residents have the right to private and unrestricted communication with anyone they choose (e.g. during in-person visits and through letters, telephone and electronic communication) and privacy regarding their medical, personal and financial affairs. Residents also have the right to privacy regarding their bodies, and all care must be given in a manner that maximizes that privacy.

## **Right to Receive VISITORS**

Residents have the right to receive visitors of their choosing. According to the federal government, "residents must be notified of their rights to have visitors on a 24-hour basis, who could include, but are not limited to, spouses (including same-sex spouses), domestic partners (including same-sex domestic partners), other family members, or friends."<sup>7</sup>

## **Right to Participate in ACTIVITIES**

Residents have the right to participate in (or choose not to participate in) social, religious, and community activities both inside and outside of the facility. For example, you have the right to participate in and promote an event, training or resource regarding LGBT equality (e.g. PRIDE parade, PFLAG support group meeting) without fear of discrimination or abuse.

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<sup>7</sup> Department of Health and Human Services. Centers for Medicare & Medicaid Services (CMS). Center for Medicaid, CHIP and Survey & Certification Group. Reminder: Access and Visitation Rights in Long-Term Care (LTC) Facilities. S&C 13-42-NH. June 28, 2013.

## **Right to be treated with RESPECT**

All residents have the right to be treated with dignity, respect and consideration and have the right to exercise their choice and self-determination. For example, all residents have the right to be addressed how they want to be addressed (e.g. using a resident's preferred pronoun) and the right to be clothed and groomed consistent with their gender identity.

## **Right to PARTICIPATE in YOUR CARE**

Residents have the right to be informed about care and treatment, participate in their own assessment and care planning and make decisions regarding their treatment, including health care choices related to gender transition. Residents also have the right to designate a legal surrogate (or, decision-maker) to act on their behalf. State laws, such as health care power of attorney and guardianship laws, govern how someone (including same-sex partners or spouses or other family of choice) can make decisions on your behalf.

## **Right to be FULLY INFORMED**

Facilities must inform residents of any changes in services, changes in care or treatment, what is covered by Medicare and Medicaid or other health care insurance and of a change in roommate or room. Facilities must provide notice before a change in roommate and be as "accommodating as possible" by considering each resident's preferences.<sup>8</sup> In regards to benefits, the federal government states that Medicare Advantage enrollees are entitled to equal access to services in the same skilled nursing facility their spouse resides in, regardless of sexual orientation. Specifically stating that, "this guarantee of coverage applies equally to couples who are in a legally recognized same-sex marriage, regardless of where they live."<sup>9</sup>

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<sup>8</sup> Department of Health and Human Services. Centers for Medicare & Medicaid Services (CMS). State Operations Manual. Appendix PP-Guidance for Surveyors for Long-Term Care Facilities. [http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/som107ap\\_pp\\_guidelines\\_ltcf.pdf](http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/som107ap_pp_guidelines_ltcf.pdf)

<sup>9</sup> U.S. Department of Health and Human Services. Press Release. August 29, 2013. <http://www.hhs.gov/news/press/2013pres/08/20130829a.html>

### Right to **CHOICE**

Residents have the right to make their own choices, including what to wear, how to express themselves and their daily routine. Residents also have the right to retain and use personal items (e.g. some furnishings, pictures). Additionally, residents have the right to room with a person of their choice, including same-sex spouses or partners, if they live in the same facility and both consent to the arrangement.

### Right to **REMAIN In the HOME**

A nursing home cannot transfer or discharge a resident unless one (or more) of the permissible reasons for transfer or discharge apply. Residents cannot be transferred or discharged due to their sexual orientation or gender identity. (See 42 CFR 483.12 for Admission, transfer and discharge rights, link to federal regulations in “Resources” section).

## Advocating for **YOUR** Rights

You have the right to voice concerns with the staff without fear of reprisal and they must try to resolve grievances promptly. Nursing home staff are required to protect all residents from abuse and report and investigate allegations of abuse. Also, residents have the right to file a complaint regarding abuse, neglect, exploitation or non-compliance with the state licensing and certification agency. There are resources available to support you and agencies responsible for investigating complaints and allegations of abuse.

To locate resources in your state, including the agencies mentioned below, you can contact **Eldercare Locator**. Eldercare Locator is a national public service to help older adults and caregivers connect with local aging and disability services including the Long-Term Care Ombudsman Program, Adult Protective Services and your state licensing and certification agency. You can reach the Eldercare Locator by calling **1-800-677-1116** or visiting [www.eldercare.gov](http://www.eldercare.gov).

You have several options in addressing your concerns and you can use these at any time depending on your comfort level with working with the facility staff or the type of concern and outcome you want:

- Share your concerns with the **facility administrator, social worker** or another **staff person**. Inquire about the facility policy for grievances and use it, but know that you are not limited to their grievance policy. Document your conversations and keep a written record of your complaint. If necessary, ask for a care plan meeting to discuss your concerns.
- Contact your **Long-Term Care Ombudsman (LTCO) Program**. Ombudsmen are advocates for residents in long-term care facilities and are trained to resolve complaints with you and on your behalf. For additional information about the ombudsman program and to locate your LTCO program, visit [www.ltcombudsman.org/ombudsman](http://www.ltcombudsman.org/ombudsman). Contact information for your ombudsman program should also be posted in your facility.
- Contact your **state licensing and certification agency**. Each state has an agency responsible for the licensing, certification and regulation of long-term care facilities and investigations of complaints. To locate your state licensing and certification agency visit [www.ltcombudsman.org/ombudsman](http://www.ltcombudsman.org/ombudsman).
- Contact **Adult Protective Services (APS)**. APS investigates reports of abuse, neglect and exploitation of elders and, in many states, individuals with disabilities. Every state has APS services, but the services vary by state. To locate APS services in your area, visit [www.napsa.now.org/get-help/how-aps-helps/](http://www.napsa.now.org/get-help/how-aps-helps/).
- Abuse is a crime. If you are a victim of abuse in addition to contacting the investigating agencies contact your **local law enforcement agency**.
- Discrimination against LGBT nursing home residents is illegal. Contact the **Lambda Legal Help Desk** for information and lawyer referrals at 1-866-542-8336 or [www.lambdalegal.org](http://www.lambdalegal.org).

## **Long-Term Care Information, Resources and Advocacy**

**National Consumer Voice for Quality Long-Term Care (Consumer Voice)** The Consumer Voice is the leading national voice representing consumers in issues related to long-term care, helping to ensure that consumers are empowered to advocate for themselves and provides information and tools for consumers, families, caregivers, advocates and ombudsmen to help ensure quality care for the individual.

[www.theconsumervoice.org](http://www.theconsumervoice.org) 202-332-2275

**National Long-Term Care Ombudsman Resource Center (NORC)** The National Long-Term Care Ombudsman Resource Center provides support, technical assistance and training to the 53 State Long-Term Care Ombudsman Programs and their statewide networks of almost 600 regional (local) programs.

[www.ltombudsman.org](http://www.ltombudsman.org) 202-332-2275

## **LGBT Aging Resources and Advocacy**

**National Resource Center on LGBT Aging** The National Resource Center on LGBT Aging is the country's first and only technical assistance resource center aimed at improving the quality of services and supports offered to lesbian, gay, bisexual and/or transgender older adults. <http://www.lgbtagingcenter.org> 212-741-2247

**Services & Advocacy for Gay, Lesbian, Bisexual & Transgender Elders (SAGE)** SAGE is a national organization that offers supportive services and consumer resources for LGBT older adults and their caregivers, advocates for public policy changes that address the needs of LGBT older people, and provides training for aging providers and LGBT organizations, largely through its National Resource Center on LGBT Aging.

[www.sageusa.org](http://www.sageusa.org) 212-741-2247

**Lambda Legal** Founded in 1973, Lambda Legal is the oldest and largest national legal organization whose mission is to achieve full recognition of the civil rights of lesbians, gay men, bisexuals, transgender people and those with HIV through impact litigation, education and public policy work. <http://www.lambdalegal.org/> 212-809-8585

**National Coalition of Anti-Violence Programs' National LGBTQ Training and Technical Assistance Center** The National Coalition of Anti-Violence Programs (NCAVP) coordinates the National Training and Technical Assistance (TTA) Center on Lesbian, Gay, Bisexual, Transgender, & Queer (LGBTQ) Cultural Competency. The NCAVP Training and Technical Assistance Center is available for direct service and advocacy organizations seeking answers, support, and strategies to become inclusive of and accessible to lesbian, gay, bisexual, transgender, and queer (LGBTQ) survivors. <http://avp.org/resources/training-center> 1-855-287-5428

**The National Gay and Lesbian Task Force** The mission of the National Gay and Lesbian Task Force is to build the power of the lesbian, gay, bisexual and transgender (LGBT) community from the ground up. We do this by training activists, organizing broad-based campaigns to defeat anti-LGBT referenda and advance pro-LGBT legislation, and by building the organizational capacity of our movement. <http://www.thetaskforce.org/> 202-393-2241

**National Center for Transgender Equality** The National Center for Transgender Equality (NCTE) is a 501(c)3 social justice organization dedicated to advancing the equality of transgender people through advocacy, collaboration and empowerment. <http://transequality.org/> 202-903-0112

**FORGE: Transgender Aging Network (TAN)** FORGE was founded in 1994 in Milwaukee, Wisconsin, and provides peer support to everyone in the transgender community. <http://forge-forward.org/aging/>

## **Nursing Home Regulations**

**Electronic Code of Federal Regulations-** Part 483 Requirements for States and Long Term Care Facilities (483.10 Residents' Rights) [http://www.ecfr.gov/cgi-bin/text-idx?c=ecfr&tpl=/ecfrbrowse/Title42/42cfr483\\_main\\_02.tpl](http://www.ecfr.gov/cgi-bin/text-idx?c=ecfr&tpl=/ecfrbrowse/Title42/42cfr483_main_02.tpl)