

The **PRIDE** of Caring

June 17, 2021

Caregiving Wasn't on My Bucket List!



WELLMED
CHARITABLE FOUNDATION



Disclaimer

LGBTQIA+ – Lesbian, Gay, Bisexual, Transgender, Queer and/or Questioning, Intersex, and Asexual and/or Ally

LGBTQIAP+ - An umbrella acronym that stands for Lesbian, Gay, Bisexual, Transgender and Two-spirited, Queer and Questioning, Intersex, Asexual, Pansexual and other marginalized orientations/identities.

FACTS ABOUT CAREGIVERS



The results from a 2020 Report on Caregiving in the U.S. conducted by the National Alliance for Caregiving found that:

NEARLY **4** in **10**

caregivers consider their caregiving situation to be **highly stressful**





FACTS ON LBGT AGING

A publication by SAGE and the
National Resource Center on
LGBT Aging

sage | Advocacy &
Services for
LGBT Elders
We refuse to be invisible®

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Services for
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LGBT Older People

LGBT older people are a diverse and widespread population, residing in every area of the country.

While the U.S. census has never measured how many LGBT people live in America, reports estimate that there are currently around 3 million LGBT adults over age 50.¹ That number is expected to grow to around 7 million by 2030.²

LGBT older people face unique challenges as we age. LGBT elders are...



LGBT CAREGIVERS

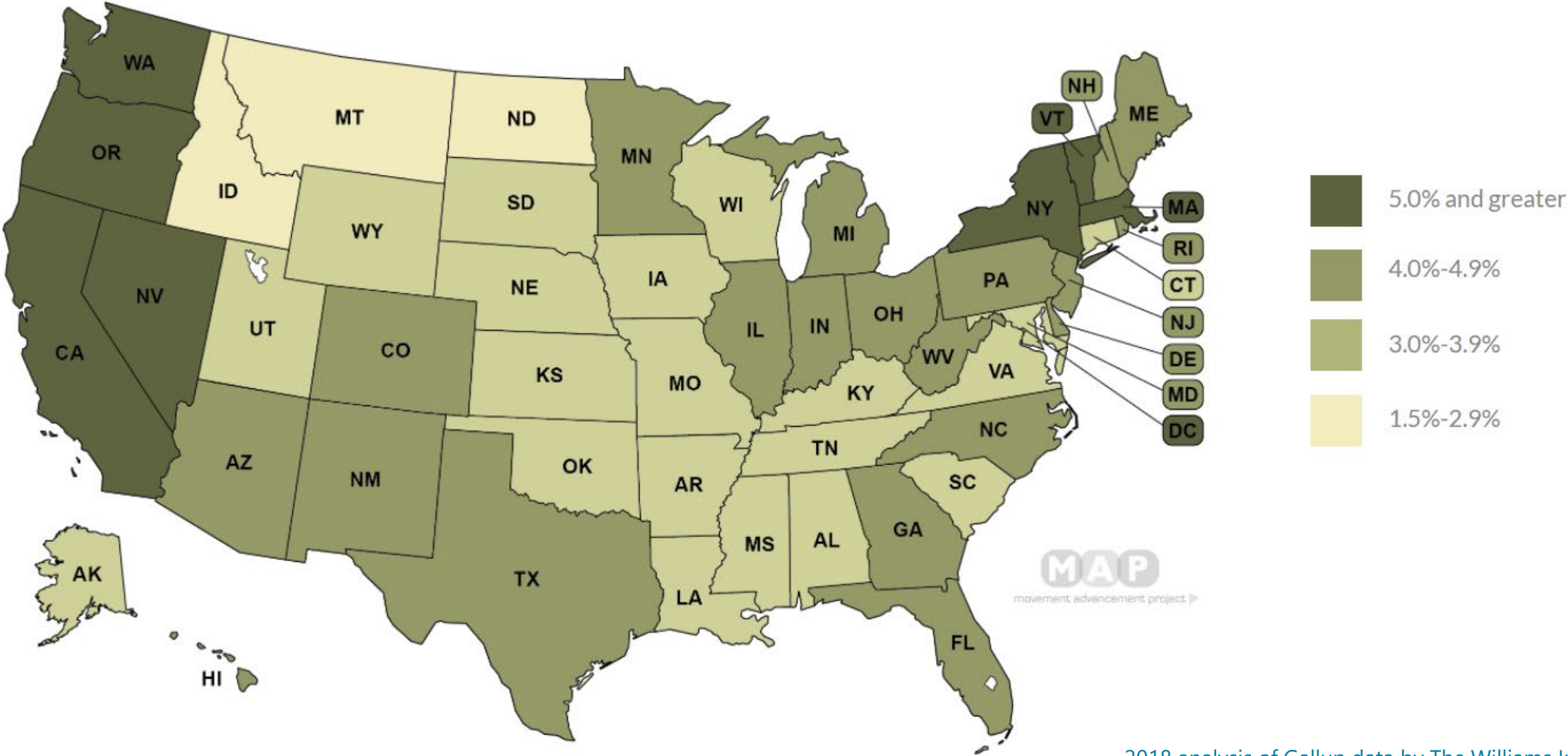


Warning signs of **caregiver burnout**

- Feeling **overwhelmed**
- Constantly **worried**
- Not getting enough **sleep**, or too much
- Gaining or losing **weight**
- **Feeling anger** at the person you're caring for
- Easily **irritated**
- **Avoiding friends** and **family**
- Feeling **sad** or **hopeless**
- Frequent **body pains**, such as headaches
- Increased use of **alcohol, drugs, or prescription medications**
- **Getting sick** more often



Percentage of LGBT Residents by State, 2018



2018 analysis of Gallup data by The Williams Institute



sage™

Services & Advocacy
for Gay, Lesbian, Bisexual
& Transgender Elders

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on LGBT Aging
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Important things for LGBT caregivers to know:

Most caregivers don't realize they are caregivers. You may just be helping out a friend or "doing what spouses do," but guess what? If you're providing any kind of ongoing support to a friend or loved one who needs assistance - cooking meals, taking them to the doctor, helping them bathe, or even just checking in on their wellbeing - you are a caregiver!

YOU define your family. The term *family caregiver* is increasingly being used to refer to those who care for family members and loved ones, in order to distinguish them from paid caregivers such as nurses, aides, or in-home health assistants. In most cases, the "family" in family caregiver is defined very broadly, and is meant to include close friends, unmarried partners, and anyone else who YOU consider family.

LGBT Caregivers are more likely to be caring in isolation & more likely to be within the same age cohort as the people they're caring for.¹ For both of these reasons, finding others who can assist, including professional service providers, is an important way to make sure that a loved one's care won't lapse due to caregiver burnout or health problems.

LGBT people become caregivers more often. *Mom is sick. Your sister's busy with her high-powered career, your brother's busy raising his kids, and you end up taking on the bulk of Mom's care.* Sound familiar? You're not alone. LGBT baby boomers and Millennials tend to take on the care of their aging parents at a disproportionate rate. Even if partnered, families often see LGBT adults as single and rely on them for caregiving. And though we may not be seen as the "sandwich generation" if we don't have kids, we're often caring for friends and members of our community at the same time, which results in the same sort of juggling act.

Caregivers tend to have poorer mental and physical health than non-caregivers.² For a population that already experiences health disparities, this is a serious concern. It's important to take care of yourself, even though you may be focused on caring for someone else. Keeping up with regular medical appointments, getting emotional support when you need it, and making time for things you love to do will help you to be a better caregiver for your loved one.



Tips to Manage Caregiving Responsibilities:

Advocate for yourself.

- Consider speaking with your own doctor about your stress level and learn ways to manage stress.
- Ask for training if you are expected to handle any procedures at home.

Recognize your emotions.

- Whatever you're feeling, it's helpful to recognize your emotions and to know that you are not alone in feeling this way.
- Finding someone to talk to about these feelings can be very helpful.

Take care of yourself.

- Allow yourself to take a break.
- Tend to your own needs for exercise, sleep, and healthy eating. There are community services to help you in your journey of caregiving.

Visit www.sageusa.org or call the SAGE Hotline at 1-888-234-SAGE.

Question:

My partner Chris and I have been together for 11 wonderful years. Chris was diagnosed with prostate cancer. The cancer was caught early enough that his prognosis is very good.

Chris and I are both employed full-time. He is on medical leave now, but because we are not married, I have been taking sick days and vacation days to attend to his care and medical appointments. I am worried about being there for him in the future to take him to treatments. I'm uncomfortable discussing this with my HR manager, and I thought about asking Chris to get married so that I'd be eligible to take medical leave.

Do you have any advice?

Employment Issues When Caregiving

The Family and Medical Leave Act (FMLA) requires most companies to offer employees at least 12 weeks unpaid leave to care for ailing family members—but does not provide job protection to domestic partners.

Many private employers now offer domestic partners the same medical leave and bereavement policies as married employees.

In June of 2020, the Supreme Court ruled that The Civil Rights Act that bars discrimination based on sex was extended also to cover gender identity and sexual orientation. This now means that an employer cannot discriminate based upon gender identity and sexual orientation in the workplace.

Human Rights Campaign

<https://www.hrc.org/resources/state-equality-index>

Lambda Legal

<https://www.lambdalegal.org/helpdesk>

National Center for Lesbian Rights

<http://www.nclrights.org/>

Caregiving Can Impact Intimacy

1. Talk openly to each other. It's natural to want to avoid awkward or sensitive subjects, but try to push through your discomfort and be honest with your partner about your needs and desires, and how caregiving is affecting both.
2. Consider talking to a psychologist or social worker. Caregiver support groups can also be a good place to vent frustrations and feel less alone.
3. Manage your expectations. We sometimes devalue things like hugging or holding hands, saying 'I love you,' saying how beautiful someone looks in a certain light — those are really the building blocks of intimacy. And remember what the relationship was like before.
4. Go on dates. You don't have to do anything fancy; just find activities where you and your partner can connect in nonphysical ways. Carve out that time to be partners, not caregiver and care recipient, just for a couple of hours.
5. Set your own rules. "There's a lot of pressure, both internal and external, to have a relationship that looks a certain



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 10.1 million Americans identify as lesbian, gay, bisexual or transgender (LGBT),¹ with 3.8% aged 52 and older individuals identifying as LGBT.² 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.³ Incidents of abuse are often unreported or unidentified; however, a majority of individuals responding to a survey (578 of the 649 respondents or 89%) felt that staff would discriminate against an LGBT elder who was out of the closet.⁴ Additionally, negative treatment, including verbal and physical harassment, by other residents was the most commonly reported problem by respondents in this study.⁵

I lived in a very rural, conservative state as a lesbian for 25 years and then transitioned from female to male. LGBT elders in (state withheld by request) are forced to remain hidden, and when placed in long-term care facilities, become even more isolated. I have done training for long-term care staff and administrators in this state, but most feel that there are no LGBT residents in their facilities. Sean, 51 years old (**LGBT Older Adults in Long-Term Care Facilities: Stories from the Field.** <http://www.lgbtagingcenter.org>)

KNOW YOUR RIGHTS⁶

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):⁷

¹ 5 Key Findings about LGBT Americans. Pew Research Center. <http://www.pewresearch.org/fact-tank/2017/06/13/5-key-findings-about-lgbt-americans/>

² 5 Key Findings about LGBT Americans. Pew Research Center. <http://www.pewresearch.org/fact-tank/2017/06/13/5-key-findings-about-lgbt-americans/>

³ 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. <https://www.metlife.com/assets/cao/mmi/publications/studies/mmi-out-aging-lesbian-gay-retirement.pdf>

⁴ 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>

⁵ *LGBT Older Adults in Long-Term Care Facilities: Stories From the Field*, loc. cit.

⁶ 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.

⁷ See 42 CFR 483.10 for complete list of federal nursing home residents' rights <http://www.ecfr.gov/cgi-bin/text-idx?ecfr=5013a140a300a1dbbea73a73921156948&rnndiv=8&viewtext&nnode=42:5.0.1.1.2.7.3&idno=42>

What to do if you have a nursing home complaint or concern

1. **Try contacting the facility first**, via phone or email. It may be able to directly address your complaint or query quicker than an ombudsman can. Before contacting the facility, learn as much as you can about the situation and be ready to clearly articulate your questions or complaints. Ask about the best way to maintain contact with the facility going forward. Take good notes, including the names of those with whom you've spoken.
2. If unsuccessful, **reach out to your ombudsman**. "No question is too big or small," Hunter says. "The beauty of the ombudsman program is that we're a jack of all trades." If an ombudsman can't address your query or complaint, you will be directed to someone who can. Also visit the [National LTC Ombudsman Program Resource Center](#), which has up-to-date information on LTC regulations, guidance and ombudsman outreach during the pandemic.
3. **Be persistent**. Although there will be no delay in the office getting back to you, a lack of access to facilities is making investigations more difficult for ombudsmen. If an issue persists, you can file a complaint with your [state survey agency](#), which inspects nursing homes to determine if they comply with Centers for Medicare & Medicaid Services regulations.

<https://www.aarp.org/caregiving/health/info-2020/long-term-care-complaints-ombudsman.html>

National Center on Elder Abuse www.ncea.acl.gov



MAINTAINING DIGNITY: THE NEEDS OF OLDER LGBT AMERICANS

When it comes to aging, older LGBT adults are most concerned about social support, discrimination, and access to health care.

76%

WORRY ABOUT HAVING ADEQUATE FAMILY AND/OR SOCIAL SUPPORTS TO RELY ON



88%

WANT LONG-TERM CARE PROVIDERS WHO ARE TRAINED IN LGBT CARE

60%

ARE CONCERNED ABOUT VERBAL OR PHYSICAL HARASSMENT IN LONG-TERM CARE FACILITIES



85%

WANT LONG-TERM CARE PROVIDERS WHO ARE LGBT THEMSELVES

Source: Maintaining Dignity: A Survey of LGBT Adults Age 45-plus, March 2018.

www.aarp.org/dignitysurvey

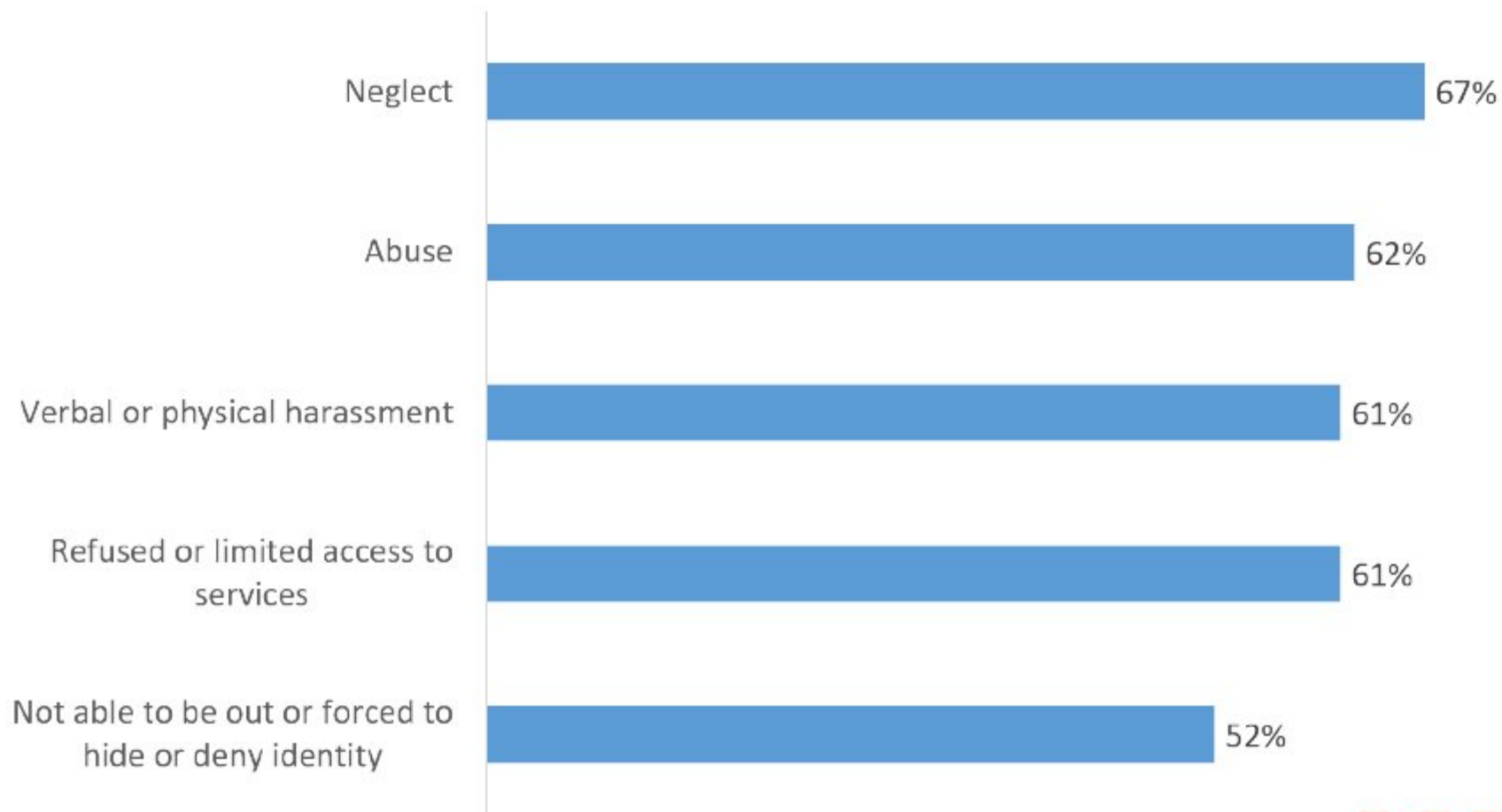
My partner Pat and I were together for 15 years but split up a few years ago. We separated a few years ago on good terms, and have remained friends. In January, Pat suffered a stroke. We live in Houston, but neither of us are originally from here and we have no family here. I didn't want Pat to go into a facility because of COVID at the time, and she came to live with me while she recovers. This has been a strain on my current relationship with my new girlfriend.

It's been months now, and it seems clear that she won't be able to live on her own for some time. Her doctors have suggested that we consider her placement in a rehabilitation hospital to help with her recovery.

You've mentioned tips for finding nursing home placements in the past that are LGBT-friendly or welcoming, but what about a rehab facility?

As an LGBT community member, if you or your spouse/partner ever needed long-term care, such as in-home assistance, assisted living or nursing home care, how concerned would you be about the following?

% Very or Somewhat Concerned among LGBT Adults Age 45 and Older



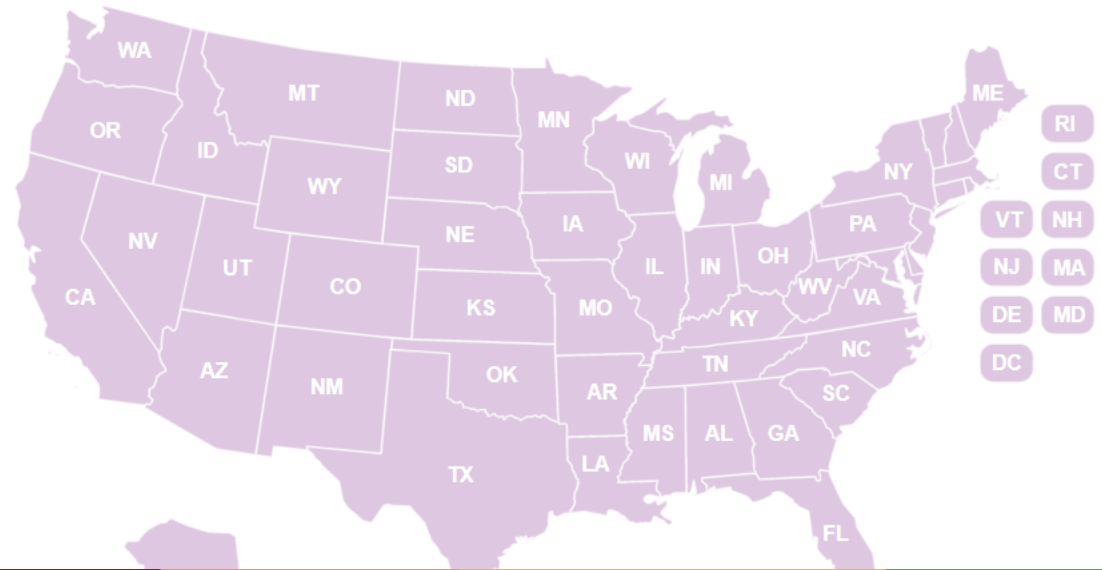
Source: Maintaining Dignity: Insights on Concerns and Preferences of Mid-Life and Older LGBT Adults

Find Resources in Your Area

All older adults, and LGBT older adults in particular, need to have certain legal and financial plans and documents in place to ensure that their wishes regarding healthcare, pensions, inheritance and more are respected. Because state laws vary widely, the National Resource Center on LGBT Aging has compiled state-by-state resources so you can find the help you need in your community. Please note: this resource will grow over time to include resources on health, housing, and more. **Tell us what you'd like see.** Read our **disclaimer policy.**

BROWSE RESOURCES

- BY AUDIENCE
- BY SUBJECT
- BY TYPE
- ADVANCED SEARCH



<https://www.lgbtagingcenter.org/>



If you've got
something to
talk about,

**WE'RE HERE
TO LISTEN.**

THE SAGE NATIONAL LGBT ELDER HOTLINE

is OPEN and ready
to take your call.

Concerns over health and housing?
Anxiety over today's political climate?
Worries about infringements upon
your civil rights in your community
or workplace? Woes over a
relationship? Feeling lonely?

GIVE US A CALL!

Our highly trained LGBT
volunteers will address any
topic you care to share.

sage™



Operated by the GLBT
National Help Center, the
SAGE LGBT Elder Hotline is
open Monday through Friday,
4pm to midnight ET, and
Saturdays, noon to 5pm ET.

CALL TOLL-FREE
1-888-234-SAGE

or email us at
SAGE@GLBTHotline.org



Resources

SAGECare for a listing of organizations trained and credentialed by SAGE: www.sageusa.care

SAGE Hotline for Peer Support and Resources: 1-888-234-SAGE or SAGE@GLBTHotline.org

CenterLink for a listing of LGBT Community Centers across the country: www.lgbtcenters.org

Lambda Legal
<http://www.lambdalegal.org>
212-809-8585

The [GLBT National Help Center](http://www.GLBTHotline.org) provides telephone, online chat, and email peer-support. They also have a [massive resource database](#) for social and support groups, gay-friendly religious organizations, social groups, and more.

1-888-843-4564
<http://www.GLBTHotline.org>



The **PRIDE** of Caring

Thank you!!

Please join us next week:

Thursday, June 24th

11:00 am Eastern
10:00 am Central
9:00 am Mountain
8:00 am Pacific

The Pride of Professionals with Dr. Elliot Montgomery Sklar and Lucy Barylak, MSW

Join this important conversation about cultural competence in health care. What can LGBTQ patients teach providers about their health care experiences? What should providers know?