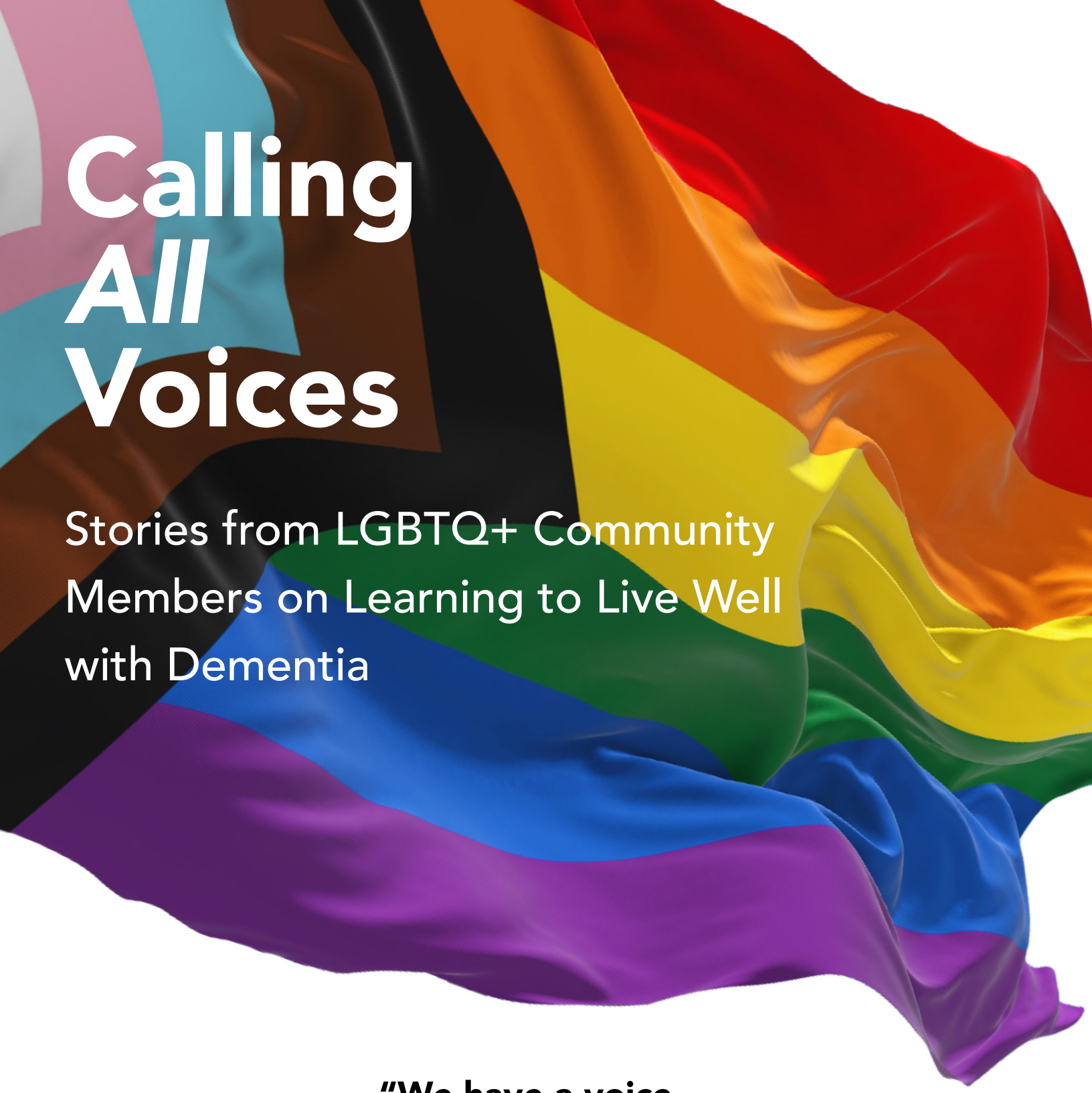

Calling *All* Voices

Stories from LGBTQ+ Community Members on Learning to Live Well with Dementia

"We have a voice, and we need to represent ourselves"

– Mary Beth Wighton, living with dementia

Global Council on Alzheimer's Disease

Dementia Action Alliance

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Introduction

In 2021, the Global Council on Alzheimer's Disease (GCAD) and Dementia Action Alliance (DAA) co-authored a first-of-its-kind paper, *Hear Our Voices*. This paper shared insights from a series of interviews of people living with dementia and their care partners, and it revealed how – along the dementia journey – people often have experiences that do not align to their expectations. This paper sought to fill a gap in the literature by offering first-hand, authentic testimony about experiences with agitation due to dementia.

That paper became a catalyst for recognizing the need to hear from more diverse voices. We believe it is important to capture the distinct experiences of dementia among people from communities that are often marginalized, underserved, and unheard.

This paper, *Calling All Voices: Stories from LGBTQ+ Community Members on Learning to Live Well with Dementia,* is the first in a *Calling All Voices* series to hear from and amplify more diverse voices. In this paper, we provide a platform for the LGBTQ+ community to share, in their own voices, their experiences living with dementia.

In the pages that follow, we share a set of "lived experiences" that we heard as we had conversations with nine members of the LGBTQ+ community, seven of whom are living with dementia and two of whom are care partners. These individuals come from diverse backgrounds and geographical regions, they have different types of dementia, and some are single while others live with a partner.

In our conversations, we heard about a series of challenges that people in the LGBTQ+ community encountered as they learned to live well with dementia. Some of these challenges are very familiar for people living with dementia, such as the difficulties encountered in the diagnostic experience. Other challenges may be less familiar, such as lack of community, a shortage of culturally-appropriate support and resources, as well as bias and discrimination – both within and beyond the healthcare system.

We would fail in our goal to hear the whole story if we only shared challenges and difficulties. Throughout our interviews, we heard stories of hope, creativity, community, and tenacity. We heard stories of perseverance and triumph. And we heard invitations to join the advocacy efforts to support the LGBTQ+ community affected by dementia.

We would like to thank the courageous people who shared their experiences with us. The insights and stories they shared are the only reason this paper came to be. At the same time, we recognize their experiences cannot – and must not – be presented as representing all experiences of the LGBTQ+ community living with dementia. To that end, we are using this paper to *call all voices* of the LGBTQ+ community to share their stories. Whether it's with GCAD, DAA, a support group, another person living with dementia, or anyone else, each voice can help to create a better, more equitable future for people living with dementia.

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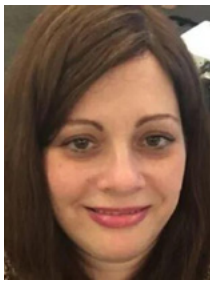

Dawn Baxter

Brian Van Buren

Patrick Ettenes

Melissa Hamkins

This project is a collaboration between the Dementia Action Alliance (DAA) and the Global Council on Alzheimer's Disease (GCAD). We would like to thank everyone who graciously shared a story with us and allowed us to share it with you. This project would not have been possible without their courageous voices.

We would also like to extend our deep gratitude to Chris Covell, President and CEO of Brain Engaging Enterprises, for her expert voice and the skill and compassion with which she led the conversations that became this paper.

Susan Balkman,
living with dementia in New Mexico

Dawn Baxter,
care partner in Canada

Brian Van Buren,
living with dementia in North Carolina

Patrick Ettenes,
living with dementia in England

Melissa Hamkins,
living with dementia in Maine

Meredith Hunt,
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Shawn Kelly,
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John-Richard Pagan,
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Mary Beth Wighton,
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Shawn Kelly

John-Richard Pagan

Mary Beth Wighton

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Dementia in the LGBTQ+ Community

What it Means to be LGBTQ+

The term LGBTQ+ serves as an umbrella term for a wide range of gender and sexual identities. According to the Human Rights Campaign, the largest LGBTQ+ advocacy group in the United States, LGBTQ+ is "an acronym for 'lesbian, gay, bisexual, transgender, and queer' with a '+' sign to recognize the limitless sexual orientations and gender identities used by members of our community."[1] Of course, people who are LGBTQ+ come from all cultures, backgrounds, and racial, religious, and ethnic groups.

The LGBTQ+ Community's History of Discrimination and Progress

The LGBTQ+ community has experienced a long history of bias, discrimination, and marginalization. Their identity has been – and still is, in many parts of the world – considered criminal behavior.[2] They have experienced discrimination from employment, housing, and healthcare. Rates of violence to the LGBTQ+ community are heartbreakingly high.[3]

In the United States, the three-day Stonewall Riots in New York City in 1969 began what many consider to be a turning point in history of advocacy for LGBTQ+ rights.[4] More recently, in 2009, the Matthew Sheppard Act was signed by the US Congress to expand the 1969 Federal Hate Crime Law to include crimes motivated by the victim's gender identity and sexual orientation.[4] And less than a decade ago, in 2015, the Supreme Court declared same-sex marriage legal in all fifty states.[4] Progress has not been unique to the U.S., globally other countries are moving to legalize same-sex marriage and offer protections to the LGBTQ+ community.[5] These milestones, of course, only paint part of the picture. Culturally, LGBTQ+ rights, advocacy, and acceptance have merged into the mainstream.

But while there has been progress, challenges persist – particularly for those in the LGBTQ+ community living with dementia. We must confront these realities and give voice to a group that is, at present, unheard. By 2030, the number of LGBTQ+ older adults living with dementia is expected to surpass one million. And the number of older adults who openly identify as LGBTQ+ is expected to at least double.[6]

Sharing will help others in the LGBTQ+ community live well with dementia and help the broader community to become more understanding and better equipped to support and advocate for LGBTQ+ individuals with dementia.

The Power of Community

> **It's always wonderful to be with your own kind."**
>
> ***- Shawn Kelly,***
> **living with dementia**

Approximately one in four adults over 65 in the United States is socially isolated, according to a report from the National Academies of Sciences, Engineering, and Medicine.[7] Older LGBTQ+ adults experience loneliness and lack of support to an even greater degree.[8] This isolation can lead to poor health outcomes, including premature death and higher rates of mental health challenges.[8]

But the reverse is also true. Building and embracing community can have powerful health benefits. People living with dementia in the LGBTQ+ community are showing what's possible.

The Barriers to Finding Community

> **For 30 years I have lived on my own, and I currently have no significant other. We don't always have a partner, or another half."**
>
> ***- John-Richard Pagan,* living with dementia**

A History of Discrimination

It is a sad fact that the majority of people within the LGBTQ+ community have experienced discrimination, with over 50% of LGBTQ+ adults reporting that they have experienced microaggressions because of their sexual orientation or gender identity.[2] While many of these experiences pre-date dementia diagnoses, they set the foundation for how individuals experience their disease journeys.

"I used to be in the service and there was someone from my high school who joined the same time I did. He told people the rumor that I was gay, so from boot camp on, I had threats on my life. I was harassed, beaten up, and abused. It all ended with the military throwing me out anyway."

- John-Richard Pagan, living with dementia

"Sometimes we had problems with the people who lived in our area. During political campaigns, we would have signs out in our yard and people would throw bottles or cans at them or drive across our lawn to knock the signs down."

- Meredith Hunt, care partner

"I took a lot of homophobic abuse as a child because I was out from a very young age. I had no choice. I was born with heels on my legs, so everyone knew."

- Patrick Ettenes, living with dementia

An Absent or Distanced Family

Much of the literature on living with dementia offers guidance for how families can provide support. However, many older adults in the LGBTQ+ population living with dementia may lack family members who can or are willing to support them. One study in The Gerontologist finds LGBTQ+ adults are twice as likely to live alone as their heterosexual peers and four times less likely to have children to help them as they age.[9] This may contribute to why nearly twice as many members of the LGBTQ+ community are concerned about growing old, compared to the general population.[10]

"A lot of us are on our own and don't have long term partners or family to take care of us."

- Patrick Ettenes, living with dementia

"Not everyone in the gay community has a birth family that supports them. Many of us are disowned because our families don't want to be involved in what they call a 'lifestyle.' In the gay community there is not always a family of origin that you can return to."

- John-Richard Pagan, living with dementia

Legacy of the HIV/AIDS Crisis

By 1995, in the United States, one in nine gay men had been diagnosed with HIV/AIDS and one in fifteen had died.[11] Between 1987 and 1998, over 324,000 men and women died of AIDS.[11] Those who survived, lost friends, partners, and support networks. As adults in the LGBTQ+ community age and become affected by dementia, these losses from HIV/AIDS reduce opportunities to build community and a network of support. These losses are especially hard for Black gay and bisexual men. The Kaiser Family Foundation finds that Black men account for 39% of infections attributed to male-to-male sexual contact despite making up less than 15% of the national population.[12]

"I knew well over 300 gay men who died from AIDS. I mean it was just like a pandemic."
- Brian Van Buren, living with dementia

> ***I'm the only person from that group still alive today...***
>
> **I don't have any friends my age who could support me. Everyone has passed away from AIDS. I remember hosting a Thanksgiving dinner in 1990 where I had 21 people around the table**
>
> **– our house was where everyone would gather when they didn't have anywhere else to go.**
>
> **I'm the only person from that group still alive today."**
>
> ***- Brian Van Buren,***
> **living with dementia**

Lack of Community-Oriented Resources that Consider LGBTQ+ Experiences

Few dementia resources, support groups, or advocacy initiatives are designed to support the LGBTQ+ community. In addition, research shows that only rarely do government-funded aging centers offer services tailored to LGBTQ+ older adults.[13] This lack of recognition contributes to a feeling of alienation among some members of the LGBTQ+ community, who may not feel recognized by or welcome in spaces for adults living with dementia.

"After the diagnosis, I found some support groups. But they were very geriatric-oriented, they were all happening at the senior center and there was certainly nothing LGBTQ+. I just didn't feel like it fit us."

- Meredith Hunt, care partner

"I am part of an alliance for gay men, and one of the things we do is work to improve health. We have done a lot with HIV and are now looking to make the health component more inclusive and expansive. I said, 'what about dementia?' The response I got was, 'that takes a lot of research and planning, it could be years before we could ever develop anything like that for the community.' Hearing that saddened and frustrated me."

- John-Richard Pagan, living with dementia

They had their wives of twenty years; they had their kids to take care of them...

I went to a support group for people with dementia, and I would come home more depressed. I would completely fall apart, and I didn't understand why.

There were older gentlemen in the group, and they would complain about Blue Badge, which allows for parking in handicap spaces. And that's all they cared about.

I sat there looking at them; they had their wives of twenty years; they had their kids to take care of them, they were supported.

It struck me, I'm 30 years old and I don't even have a boyfriend. Who is going to take care of me? I literally burst into tears. I told them, 'You all are complaining, but you have everything that I don't have. I don't know how I'm going to cope in the future.'

One of the gentlemen said to me, 'just go on an app, you'll find yourself a boyfriend, he will take care of you.' To him, it was so simple, just go online and find someone."

- Patrick Ettenes,
living with dementia

Overcoming the Barriers

> **I would not have been as bold if I had not had my community."**
>
> *- Susan Balkman,* living with dementia

Forming Support Groups

Support groups can help people living with dementia to find advice, empathy, and understanding. But not all support groups are tailored or hospitable to the LGBTQ+ community with dementia. That's why some individuals from the LGBTQ+ community have formed their own. Their goal is to allow LGBTQ+ individuals with dementia and their care partners to share and relate to one another's experiences.

"I couldn't find support networks for LGBTQ+ people, so I would complain about it at meetings and to organizations. Finally, someone said to me, 'just go and develop one, make the first.' So, I ended up making one of the first LGBTQ+ dementia networks in the world. It ended up becoming an innovation project with the Alzheimer's Society."

- Patrick Ettenes, living with dementia

"In Canada I've felt like I'm the only gay person with dementia. But, I've found a few people in the U.S. Many years ago, now, there was group of six of us. I was the only one from Canada, the rest were from the States. And we came together to talk. It felt good to be part of a group that was positive."

- Mary Beth Wighton, living with dementia

> ***We've come together and formed our own group...***
>
> **In my support group for female spouses of people with dementia, the majority of members were heterosexual. There were always comments like 'my husband does this, does your husband do this?'**
>
> **Well, I have a wife, so I contacted the woman who founded the group and got her to rewrite the description of the group to make it more inclusive.**
>
> **As a result, there have been others who have acknowledged they have same-sex partners. We've come together and formed our own smaller group for LGBTQ+ spouses."**
>
> *- Meredith Hunt,* care partner

Creating Support Systems

Many LGBTQ+ individuals living with dementia have found ways to build their own systems of support. They are using technology, peer support, therapists, and in some cases workplace resources.

"I have two roommates: Siri and Alexa who help me with things like remembering my keys. I have also developed a treatment team right from the beginning. I had my speech therapist, a life coach who really helped me get through the emotional issues, and my neurologist. I even had my church involved."

- Brian Van Buren, living with dementia

"The LGBT Foundation was like my family. It was all I had, that's the place I went to, and it was my safety net, they literally adopted me like a stray cat. And that is where my chosen family started."

- Patrick Ettenes, living with dementia

"I've found a lot of support from my partnership with Dawn... Dawn knew what I was capable of and am still capable of, and she wasn't going to have any of this, 'woe is me' talk. She said 'you need to pick it up. You're not going to drink; your family still needs you, and I need a partner. We have life to live.' I think it's important that we have some expectations of people, because when you don't, you're not supporting the person."

- Mary Beth Wighton, living with dementia

Overcoming Bias in Medical and Care Settings

> You have to become your own advocate."
>
> *- Dawn Baxter,*
> **care partner**

It is no secret that high-quality care – both medical and non-medical – contributes to living well with dementia. A recent study, for example, found that quality of care can have a positive effect on quality of life for people living with dementia.[14]

For the LGBTQ+ community, however, bias, harassment, and discrimination may form roadblocks to receiving quality care. In response, LGBTQ+ individuals have pushed to create more inclusive spaces which has encouraged other LGBTQ+ people to step forward, get the care they need, and ensure their voices are heard.

An Erosion of Trust

> **You have your own prejudices, and sometimes those prejudices come forward without you even realizing."**
>
> ***- Patrick Ettenes,***
> **living with dementia**

Healthcare and Medical Settings

There is a growing body of literature that shows how implicit bias of healthcare practitioners affects the care that people receive. This bias applies not only to race, class, and ethnic background, but also gender and sexuality. One recent study, for example, found that heterosexual providers had implicit preferences that favored heterosexual people over LGBTQ+ individuals.[15] Another study revealed that nearly half of heterosexual first-year medical students expressed at least some explicit bias and over four-in-five held implicit bias against gay and lesbian individuals.[16]

These biases can complicate the already-difficult process of seeking quality medical care for LGBTQ+ individuals. In some cases, fear of discrimination prevents people from seeking care altogether. A recent study found that nearly one-in-five LGBTQ+ adults avoid seeking healthcare for themselves or family members due to concerns about discrimination.[3] For racial minorities, the burden is even greater.[17]

> "I definitely felt that we weren't taken as seriously or heard because we were two women."
>
> *- Dawn Baxter, care partner*

> "Once when I was waiting in the VA to give blood, the news on the TV suddenly switched to footage of the pride festival. The veterans around me started making horrific jokes and comments about gays and lesbians. I sat there, and all I wanted to do was hide in a hole. There was another time where a doctor actually asked me if I played with dolls as a kid. He didn't have any reason to ask that kind of question, it just dumbfounded me."
>
> *- John-Richard Pagan, living with dementia*

Residential Care Settings

In a survey of older LGBTQ+ adults, less than a quarter believed they could be open with their gender identity or sexual orientation with staff in long-term care facilities. Many shared that they felt at-risk for abuse, neglect, or discrimination.[18] This concern was reflected in the research for this paper, as well.

> ***The nurse refused to recognize them as a married couple...***
>
> **My mother stayed in a long-term care facility. There was a gay couple who lived there, and the nurse refused to recognize them as a married couple. The nurse went so far as to leave bibles in their room so they could 'find God and get cured.'"**
>
> ***- Brian Van Buren,***
> **living with dementia**

"The thought of being in an assisted living home with a bunch of people who see no place for someone like me? No thank you, that's not living."

- John-Richard Pagan, living with dementia

"In a care home you're vulnerable, and that vulnerability can cause people to stay quiet. Many older LGBTQ+ people are getting care from the straight community they may have run from. I knew people who hid pictures of their partners from caregivers. They fear ridicule and traumatization, that's enough for them to shut down."

- Patrick Ettenes, living with dementia

"I haven't made the fact that I'm gay as public in my assisted living residence. Some people are more accepting than others."

- Shawn Kelly, living with dementia

Advocating for Themselves and Others

> **It was important for us to share our story because that was the only way to get people to understand it...**
>
> **To see that this is dementia, and this is still an active member of the community."**

- *Melissa Hamkins,* living with dementia
***Meredith Hunt,* care partner**

Inclusivity

Small changes can make big differences – differences that can make places feel welcoming, inclusive and safe for the LGBTQ+ community.

"It's nice when there is somebody who is LGBTQ+ working in the clinic. It's nice to have somebody who is familiar, who is representative of you."

- Susan Balkman, living with dementia

"It's important for us to go to an establishment and see that there is a gay flag, because that's our little sign, when we see it's there, we can usually say 'it's ok, they're friendly enough."

- Patrick Ettenes, living with dementia

> ***Acknowledge their community exists...***
>
> **In my clinic we use tangible items to help signify we are a safe space. Waiting rooms have LGBTQ+ magazines, we have the transgender flag, and the rainbow flag. I wear a button on my scrubs with my name and pronouns. It helps people assume it's okay, that they are welcome. And it's not only for LGBTQ+ people, it's also for African Americans and Native Americans; it's about having things that identify you acknowledge their community exists."**

- *Meredith Hunt,* care partner

Becoming an Advocate

In response to experiences of bias and discrimination, individuals living with dementia in the LGBTQ+ community have become advocates for themselves and others. These efforts have helped increase awareness and acceptance in the broader community.

"I realized I needed to stand up and tell people my story because that was the only way they were going to learn … I ended up helping to create something called the Ontario Dementia Advisory Group, the first of its kind in Canada. We were teaching, in particular, Alzheimer's Societies that we, people living with dementia, have a voice that is not being represented. We said, 'we need to represent ourselves, you can help to do that, but don't speak for us."

- Mary Beth Wighton, living with dementia

"It's really important that people with dementia stay engaged. Go to the dementia unit in a nursing home and see what they're doing, if you don't see people engaged, go to the director's office immediately. Camp out there every day if you have to. I've done it before."

- Susan Balkman, living with dementia

"I always had a rainbow flag flying and I always greeted my neighbors with a smile. If somebody asked me questions like 'who is the man in the relationship,' I would respond. I want to educate people. If you don't say something, you'll never educate them. I want to be able to answer their questions honestly, their question may be their desire to know more."

- John-Richard Pagan, living with dementia

"If you're not happy with your doctor or the way you're being treated, you can go on to the next, you can keep on pounding doors. This is your life, your health, and you only get one crack at it. You become the expert of yourself during this search."

- Dawn Baxter, care partner

Learning to Live Well with Dementia

> **Dementia is about becoming vulnerable enough to say, 'this is what's happening to me.'"**
>
> ***- Susan Balkman,***
> **living with dementia**

For all the challenges, difficulties, and injustices that we have outlined in this paper, we would like to spotlight that despite the struggles, members of the LGBTQ+ community are showing an amazing spirit that they can and will live well with dementia.

Experience with Diagnosis

> **The doctor informed me that he believed I had a neurodegenerative disease, and then he said, 'have a good day, we'll talk in a few months.' I was left sitting in an empty room with the fact that I had dementia."**
>
> ***- John-Richard Pagan,* living with dementia**

Like so many people who live with dementia, members of the LGBTQ+ community often have a poor experience getting a diagnosis. The challenges can be exacerbated by insensitivity, bias, dismissal, or lack of support from those giving the diagnosis or assisting in the diagnostic process.

"The doctor was pretty inappropriate with what he was doing and what he was saying. He was also talking to me more from a clinical perspective, so I had to go home and look everything up."

- Susan Balkman, living with dementia

"I was struggling to get my diagnosis, and I was afraid that if I mentioned anything about my work in HIV the doctors would blacklist me, because they were afraid that the connection between HIV and dementia would cause panic and added stigma."

- Patrick Ettenes, living with dementia

She might be gone tomorrow...

It took us four years to get the correct diagnosis. When we got it, the geriatrician said 'you have probable frontotemporal dementia, you cannot drive effective immediately, and Dawn your caregiver will experience financial stress and she will basically be burdened by you. Ultimately, you will go into long term care and die.'"

"It took four years because we had the added pressure of Mary Beth being so young. We went to different cities like London, Toronto, Kitchener, and Waterloo. It was difficult because symptoms would appear, and it would come across as different things. First it was depression, then it was bipolar, then PTSD, and then it was conversion disorder. At one point we were told Mary Beth was just being manipulative and we were having marital problems. It was wild stuff. There was one doctor that told us 'If it ends up being something like Alzheimer's or dementia it's game over. So, you better pray that that's not it.'

When we finally got the diagnosis, I didn't understand what was going on, I was excited for a minute. I thought 'there's going to be a pill and we're good.' The doctor looked at me and she said, 'it's terminal, you need to go home and get your affairs in order.' There was nothing positive about it. We were basically handed a pamphlet and told 'this is the end of the line, good luck, there are no resources other than to call the Alzheimer's Society.'

The doctor's presentation upset Mary Beth so much that she got up and threw stuff around the room, left the office, slammed the door, and took off. So, we went home, and we laid on the couch head-to-head, and we held hands bawling. I was thinking 'oh my God like she could just wake up dead, she might be gone tomorrow.'"

- *Mary Beth Wighton,* living with dementia
Dawn Baxter, care partner

Embracing the Diagnosis

> **This is going to change your life but there's a lot of living left to do. You got to get busy…Take the time to think about how you want to live your life. And then live it."**
>
> ***- Mary Beth Wighton,* living with dementia**

The period after a dementia diagnosis can be filled with a sweeping range of emotions. Some experience fear, frustration, uncertainty, and distress. Others may experience relief because they are finally able to pinpoint what has been happening. Among the individuals we interviewed, many characterized their diagnosis as a turning point, one where they felt called to create a meaningful life with dementia, to re-learn lost capabilities, and to become advocates for themselves and others. For some, it was a public turn. For others, it was private.

"Being gay has taught me that I have to find pride in who I am and be okay with who I am. What other people think is not important. When I was first diagnosed with dementia I thought, 'okay don't tell my family', but after a while I realized 'you know I'm not ashamed of it, it's part of who I am.' I think it was important for me to then be able to say, 'here I am fully, we can talk about what it means to live with dementia, and we can talk about what it means to be a gay man living with dementia.' For me it's more than just pride, it's a joy in living this life today as the person that I was created to be."

- John-Richard Pagan, living with dementia

"I found coming out with dementia took the pressure off. I wanted to put the blame on something because I wasn't the person I used to be. For me coming out was actually relieving."

- Mary Beth Wighton, living with dementia

> ***I stood up and announced to the room that I had been diagnosed with Alzheimer's...***
>
> **At first, I didn't share my diagnosis. But there was a couple who wrote the book Before I Forget that talks about the experience of living with dementia as an African American person. They were doing a book tour around the United States, and I saw it in the paper. I got so excited because I had felt like I was the only one. So, I went to their book signing and after they spoke, I stood up and announced to the room that I had been diagnosed with Alzheimer's. I was so overwhelmed I just broke down crying. Then Dan, the husband, came from the stage and embraced me. He said, 'brother I got you, you're not alone.' He said, you need to realize now that you're out, you need to be a spokesperson, you need to carry on the torch for other people.' So that's kind of how I became an advocate."**
>
> ***- Brian Van Buren,***
> **living with dementia**

Members of the LGBTQ+ community with dementia are finding ways to maintain hope and activity in their lives. Some have even felt a heightened sense of purpose. For many, the dementia diagnosis becomes a new start to their life story.

"I try to use my humor as much as I can, to laugh at myself, and to help other people laugh at their situations. To me, it is the best healing, it's energetic, it's cleansing."

- Shawn Kelly, living with dementia

"There are choices to be made. Are you going to lie on that couch, or are you going to stand up and fight? Mary Beth stood up to that diagnosis; that was not going to be the end of her, that was the beginning of her story."

- Dawn Baxter, care partner

I taught myself to talk again...

After I was diagnosed, my doctor said to me, 'what do you love to do creatively'? And I said 'clay.' And she said, 'then that's what you need to go do.' So, I would go just like I was going to a job. From nine o'clock in the morning to, initially, five o'clock or six o'clock and then it was seven or eight o'clock because I loved it. That process of touching and feeling the clay and having that memory in your hands, is really vital to your brain connecting. It starts those synapses communicating again.

At the time I wasn't able to communicate very well, and I had difficulty with numbers. So, there were two things I did: When I couldn't remember how to say something like 'wheel' the people around me, who were other clay people, said the word and I asked them to spell it. Then I would spell the word and say it. I also started selling my pots at the market, I decided I could take my phone and use it to do the mathematics and then, if I couldn't remember words, I would look them up, and I would say them or I would ask somebody 'say that word to me again.' I did that for I quite some time, and that's how I taught myself to talk again because I couldn't. I also ended up having a new business and that's what I still do."

- Susan Balkman,
living with dementia

Call to Action - Supporting LGBTQ+ People Living with Dementia

This paper reveals a set of challenges facing the LGBTQ+ community living with dementia. But it also shares stories of how people are responding with courage, activism, and hope. In order to foster needed change around inclusivity, and continue the great progress noted at the beginning of this paper, we offer three calls-to-action. These outline ways each one of us can support members of the LGBTQ+ community who are living with dementia.

1. Help Create Community

- Volunteer at a care home to spend time with older LGBTQ+ individuals with dementia, especially individuals who are living alone or may be socially isolated.
- Support or advocate for the establishment of LGBTQ+ spaces in care homes and dementia organizations.
- Seek out your local LGBTQ+ community center, church group, online LGBTQ+ dementia support group, and introduce yourself as a friend and ally. Listen, learn, and engage.

"This is not a disease that is catchable or contagious, it's part of your community."

- John-Richard Pagan,
living with dementia

"We're just human beings, that's all we are, trying to have a life. Just like trees are trees; sometimes they have leaves on them, and sometimes the leaves fall, and that means that tree is bare and vulnerable. That's what happens with dementia, you become vulnerable. So, for the people who can't communicate verbally, watch them carefully. Watch their face and watch their eyes, they are talking to you."

- Susan Balkman,
living with dementia

2. Stand Up Against Bias – And Reflect on Your Own

- Educate yourself on the history of LGBTQ+ marginalization and the fight for equal rights.
- Take time to reflect on the explicit or implicit biases you may carry and encourage others to do the same.
- Speak up if you hear a slur or witness discrimination.
- Speak up if you hear a misconception or witness fear regarding dementia.
- Encourage the spaces you frequent (doctor's office, dentist, grocery stores, etc.) to display pride flags or other signifiers of a safe space.
- Ask people for their pronouns and share your own.
- Ask if people have a partner rather than "husband" or "wife."

"There's no halo that goes above your head and suddenly people become respectful and understanding of other cultures and other people and their way of living."

- Patrick Ettenes, living with dementia

3. Fill the Resource Gap

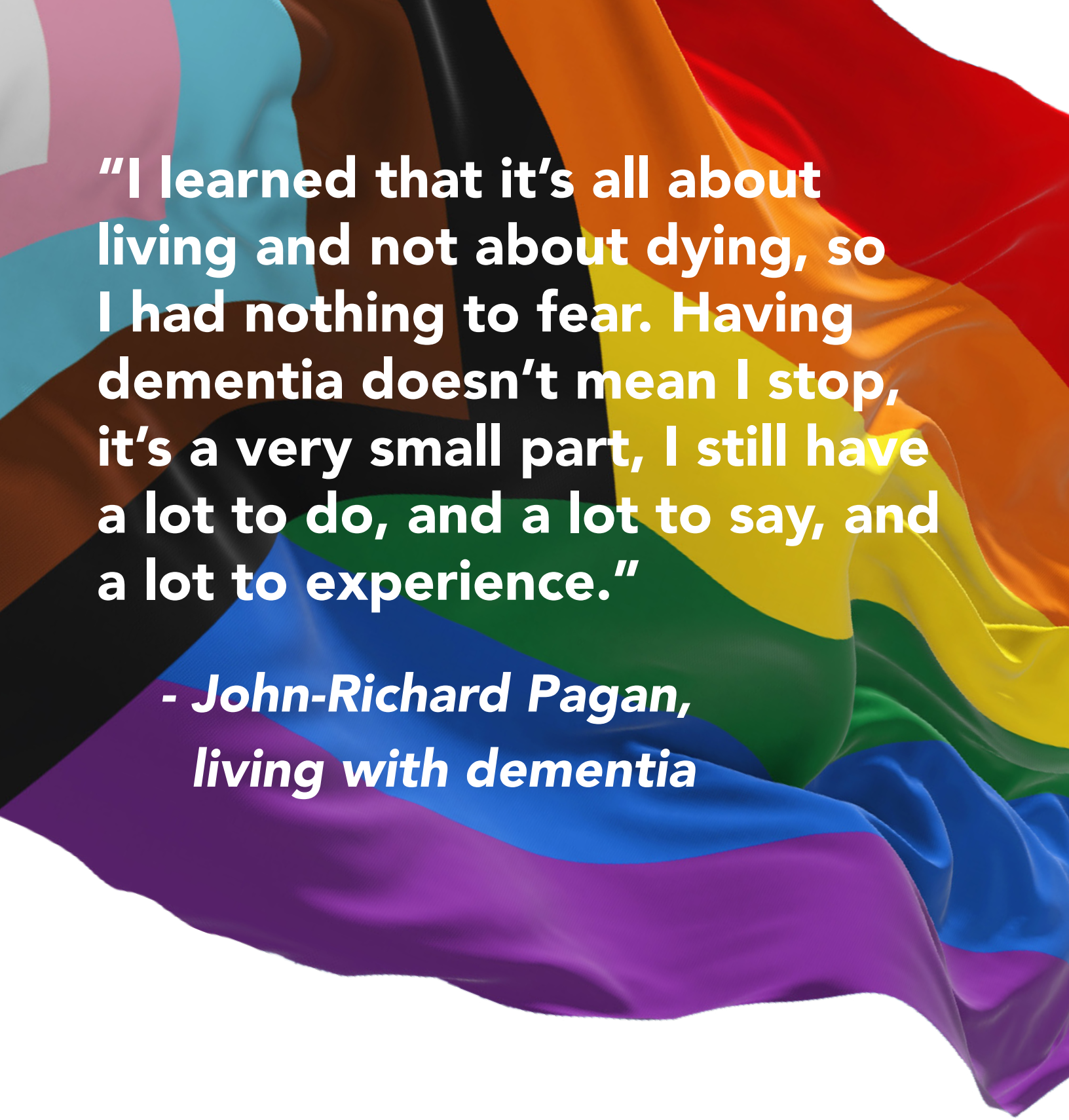
- Support dementia groups who provide resources for LGBTQ+ individuals with dementia.
- Petition your local, state, or national government representatives to prioritize improving resources for LGBTQ+ individuals with dementia.

"I wish that, if nothing else, they had somebody with a little bit of counseling background, who could come in and said let's talk about what this means going forward. Not about what it means at the end, but what it means going forward."

- John-Richard Pagan, living with dementia

"I learned that it's all about living and not about dying, so I had nothing to fear. Having dementia doesn't mean I stop, it's a very small part, I still have a lot to do, and a lot to say, and a lot to experience."

- John-Richard Pagan, living with dementia



"I learned that it's all about living and not about dying, so I had nothing to fear. Having dementia doesn't mean I stop, it's a very small part, I still have a lot to do, and a lot to say, and a lot to experience."

- John-Richard Pagan, living with dementia

Publications

Issues Brief: LGBT and Dementia

- **Alzheimer's Association**

This briefing provides information about the LGBT population with dementia along with key issues and recommendations.

We are Still Gay: An Evidence Based Resource Exploring the Experiences and Needs of Lesbian, Gay, Bisexual and Trans Australians Living with Dementia

- **Alzheimer's Australia**

This resource is an example of pioneering action research: it points the way forward to meeting the real needs of LGBTI people living with dementia. It will be invaluable as a staff training resource for service providers wanting to actively engage with the diversity of their clients. It will also assist advocacy organizations to raise public awareness of the issues experienced by LGBTI people living with dementia.

Dementia and the Lesbian, Gay, Bisexual and Transgender (LGBT+) Community: Roundtable discussion briefing paper

- **Dementia Action Alliance UK**

This briefing paper has been produced to launch the Dementia Action Alliance's (DAA) campaign to improve care and support for people affected by dementia from seldom heard groups.

LGBTI and Dementia: For People Living with Dementia who are Lesbian, Gay, Bisexual, Transgender or Intersex (LGBTI), Their Care Partners, Family and Friends

- **Dementia Australia**

This guide is based on discussions, consultations and input from LGBTI people.

LGBTQ+: Living with Dementia

- **Alzheimer's Society**

A booklet for the LGBT+ community with dementia. It has information and advice about how to live well with dementia.

Dementia, Intimacy, and Sexuality

- **Alzheimer's Society of Canada**

An overview of how dementia may affect intimacy and sexuality

Websites

LGBTQ+: Living with dementia

A page from the Alzheimer's Society about LGBTQ+ people and dementia

Proud to Care: LGBT and Dementia (A Healthcare Guide)

A healthcare guide about the LGBT community and dementia

LGBT Dementia Support

A page from Dementia Support about LGBT people and dementia

Bring Dementia Out

A new program by the LGBT foundation to address the challenges faced by LGBT people living with dementia and those who are supporting them.

Books

Lesbian, Gay, Bisexual and Trans* Individuals Living with Dementia: Concepts, Practice and Rights,

- **Edited by Sue Westwood, Elizabeth Price Year 2016**

This collection focuses on LGBTQ+ individuals living with dementia. It brings together original chapters from leading academics, practitioners and LGBTQ+ individuals living with dementia

Videos and Films

Edie: A Day in the Life of a Lesbian with Younger Onset Dementia

- **Produced by: Val's Café, 2015**

This short film follows the everyday experiences of Edie, a lesbian with younger onset dementia

LGBTI People Kindness and Dementia, by Catherine Barrett

- **Dementia Alliance International**

This presentation by Dr Catherine Barrett outlines the work of the Celebrate Ageing program, including the Museum of Love – which explores the importance of love in the lives of people with dementia. It then outlines the key challenges that lesbian, gay, bisexual, trans and intersex (LGBTI) people face when they are diagnosed with dementia.

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