

ACTING IN ALLYSHIP WITH 2SLGBTQI PEOPLE LIVING WITH DEMENTIA

Guiding Principles for Healthcare
and Social Service Professionals

February 2023

Egale

NIA NATIONAL
INSTITUTE
ON AGEING 

LAND ACKNOWLEDGMENT

We would like to begin by acknowledging that Egale is based on the traditional shared territories of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples. The territory is protected by the Dish With One Spoon Wampum Belt Covenant, an agreement between the Haudenosaunee, Anishinaabe and allied nations to peaceably share and care for the resources around the Great Lakes. The concepts of gender, sexuality, and oppression that we often rely on in 2SLGBTQI advocacy work are largely based in White, Western, colonial systems of thought and do not represent the multitude of understandings of identity that exist outside of this viewpoint. Colonial violence created the foundations for the landscape of gender-based violence that we understand today. Indigenous communities and Two Spirit activists, scholars, writers, and artists have gifted us with ample tools to work with as we move toward the collective liberation of gender and sexuality minority people. We are grateful to carry these with us here and in our work beyond. The violence of colonialism is ongoing. So too are movements toward resisting this violence.

ACKNOWLEDGEMENTS

Egale is Canada's national 2SLGBTQI organization. Egale works to improve the lives of 2SLGBTQI people in Canada and to enhance the global response to 2SLGBTQI issues. Egale achieves this by informing public policy, inspiring cultural change, and promoting human rights and inclusion through research, education, awareness, and legal advocacy. Our vision is a Canada, and ultimately a world, without homophobia, biphobia, transphobia and all other forms of oppression so that every person can achieve their full potential, free from hatred and bias.

The **National Institute on Ageing (NIA)** is a public policy and research centre based at Toronto Metropolitan University (formerly Ryerson University). The NIA is dedicated to enhancing successful ageing across the life course. It is unique in its mandate to consider ageing issues from a broad range of perspectives, including those of financial, psychological, and social well-being. The NIA is focused on leading cross-disciplinary, evidence-based, and actionable research to provide a blueprint for better public policy and practices needed to address the multiple challenges and opportunities presented by Canada's ageing population. The NIA is committed to providing national leadership and public education to productively and collaboratively work with all levels of government, private and public sector partners, academic institutions, ageing related organizations, and Canadians.

AUTHORS AND CONTRIBUTORS

Authors

Dr. Ashley Flanagan,
Research Fellow
National Institute on Ageing,
Toronto Metropolitan University

Dr. Celeste Pang,
Senior Research Officer
Egale Canada

Contributors

Dr. Samir Sinha,
Director of Health Policy Research
National Institute on Ageing

Chett Bradley, MEd
Instructional Designer
Egale Canada

This project was funded by a Dementia Community Investment grant from the Public Health Agency of Canada. The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.



Public Health
Agency of Canada

Agence de la santé
publique du Canada

ISBN: 978-1-77417-055-7

© National Institute on Ageing, Toronto Metropolitan University and Egale Canada 2023

CONTENTS

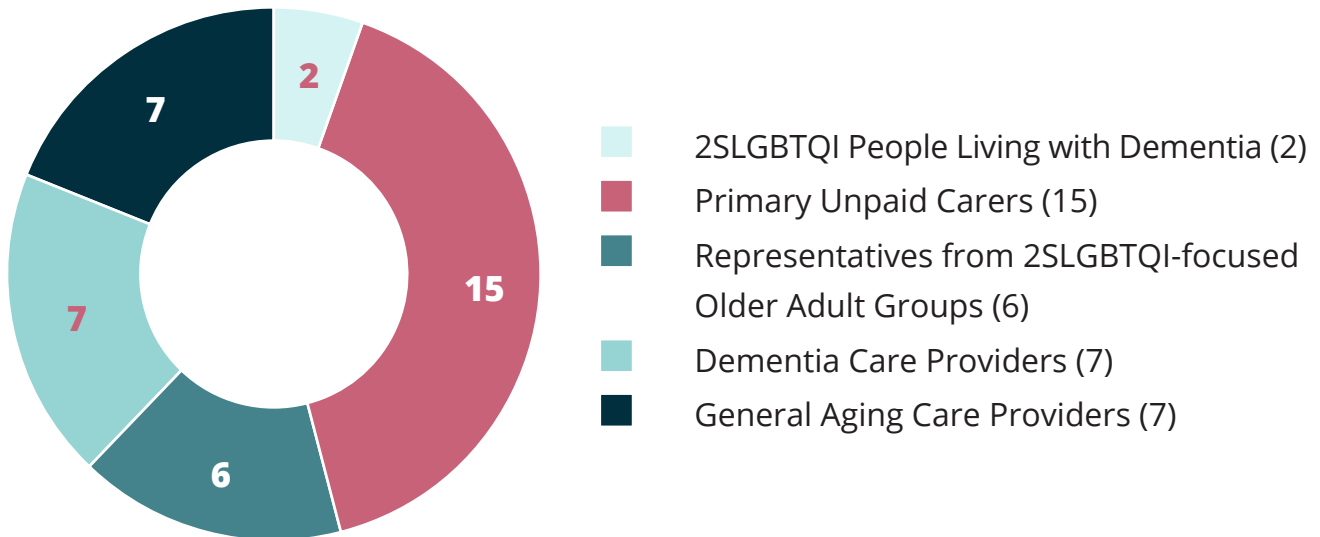
Introduction	6
Guiding Principles	7
Key Terms	9
Principle #1: Respect Identities and Expressions	10
Practical Examples	11
Helpful Resources	12
Principle #2: Recognize Diverse Experiences of Living and Caring with Dementia	14
Practical Examples	15
Helpful Resources	16
Principle #3: Speak Up and Stand in Solidarity	18
Practical Examples	20
Helpful Resources	21
Principle #4: Build Bridges	21
Practical Examples	21
Helpful Resources	22
Principle #5: Keep Learning	23
Practical Examples	23
Helpful Resources	23
Select Research	25
Conclusion	28

INTRODUCTION

What are the unique experiences and needs of Two Spirit, lesbian, gay, bisexual, trans, queer, and intersex (2SLGBTQI) people living with dementia and those who care for them? What is the current state of unpaid care as experienced or perceived by 2SLGBTQI people living with dementia and their primary unpaid carers? And how can people, organizations, and institutions across sectors come together to enhance care provision and support?

In response to these clearly identified gaps in knowledge and a growing need for shared understanding, resources, and critical inquiry, Egale Canada partnered with the National Institute on Ageing (NIA) to pursue primary research focused on better understanding the experiences and perspectives of 2SLGBTQI communities on living with dementia, and on providing unpaid care.

Through 2020-2021, we spoke with 2SLGBTQI people living with dementia, primary unpaid carers, and healthcare and social service providers and advocates from across Canada.



We learned from them about their needs and challenges, the ways that they mobilized care and resources, and their recommendations for how healthcare and support services could be improved. We identified key findings and recommendations from these learnings, research findings that we have translated into several education and awareness-raising resources.

To date, these resources include:

- A [research report](#)
 - [Coming Out and Coming In to Living With Dementia: Enhancing Support for 2SLGBTQI People Living with Dementia and their Primary Unpaid Carers](#)
- Two [e-learning modules](#)
 - [2SLGBTQI Identity and Dementia: An Introduction for Unpaid Carers](#)
 - [2SLGBTQI Identity and Dementia: An Introduction for Healthcare and Social Service Professionals](#)
- Accompanying resources
 - [Additional Learning Resources for Carers](#)
 - [Additional Learning Resources for Healthcare and Social Service Professionals](#)
 - [How to be an Ally to 2SLGBTQI People Living with Dementia](#)
 - [Nice to Meet You: What I'd like Healthcare and Social Service Providers to Know About Me](#)
 - [Recommendations for Supporting 2SLGBTQI People Living with Dementia and their Carers through Systemic Change](#)

These resources can be found at: <https://egale.ca/egale-in-action/2slgbtqi-dementia-care/>

We have also given invited presentations to numerous healthcare and social service providers groups and in major academic conferences to audiences from across Canada. A presentation overview of the research findings can be accessed here: <https://www.youtube.com/watch?v=cIKHEPWsLsY>

GUIDING PRINCIPLES

This document synthesizes research findings and recommendations—with considerations from current available research, existing relevant best practices and guidance, and expert opinion—into five guiding principles for better supporting 2SLGBTQI people living with dementia and their primary unpaid carers. This document is for:

- Healthcare professionals who provide primary and/or tertiary care
- Healthcare professionals who develop policies and programs
- Social service providers who provide programs and services to support health and wellbeing

The guiding principles outlined in this document were developed to complement existing skills and competencies and offer pathways for ongoing learning, rather than provide a repository of best practices or checklist of step-by-step processes.

Guiding Principles—or **Guidelines**—are tips, tricks, notes, or suggestions for addressing frequently asked questions. Guidelines may not necessarily be directly applicable to one’s professional practice or recognized by consensus as the “best” method or technique. Within this document, guidelines provide useful information for advancing knowledge and understanding in ways that will help healthcare and social service professionals to act in allyship with 2SLGBTQI people living with dementia and their primary unpaid carers.

Best Practices are benchmark implementation practices (e.g., methods, techniques) that have consistently provided results that are superior to other practices. Best practices are recommendations that are considered to be the “best” in most cases and in most contexts. For example, best practices might be used as a checklist for directing the implementation and evaluation of a program or service.

To better support 2SLGBTQI people living with dementia (PLWD) and their primary unpaid carers, this guidance document outlines five key principles for providing inclusive, equitable, and affirming care:

1. Respect identities and expressions
2. Recognize diverse carers
3. Speak up
4. Build bridges
5. Keep learning

Each of the following sections discusses one of these five key principles, beginning with a brief introduction, followed by practical examples and/or case studies, and concludes with suggestions for helpful resources. It is our hope these guidelines will be built upon in future research, policy making, program planning, and service delivery, as well as spur further conversations and reduce stigma about dementia in our communities.

KEY TERMS

2SLGBTQI: Two Spirit, lesbian, gay, bisexual, trans, queer, questioning, and intersex. The order of the acronym beginning with Two Spirit recognizes the presence of Two Spirit and Indigenous peoples across Turtle Island, and the historical erasure of Two Spirit people through settler colonialism and in mainstream queer organizing. For definitions of common identity terms including the ones mentioned in this acronym, see: <https://egale.ca/awareness/glossary-of-terms/>

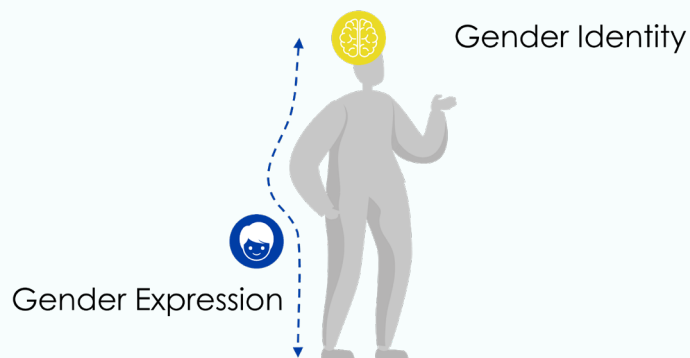
Dementia: An umbrella term referring to a progressively debilitating disease that erodes cognitive and functional abilities of individuals. While the most common form of dementia is Alzheimer's disease, there are numerous additional types of dementia including Vascular dementia, Frontotemporal dementia, and Lewy body dementia, among others (Sinha, 2012).

Person/people living with dementia (PLWD): In line with person-first language, person/people living with dementia recognizes that living with dementia is one aspect of an individual's experience, recognizing that a person is not reducible to their abilities, conditions, or diagnoses.

Primary unpaid carer: According to The Change Foundation (2016), primary unpaid carers, or caregivers, are "the people – family, friends, neighbours – who provide critical and ongoing personal, social, psychological and physical support, assistance and care, without pay, for loved ones in need of support due to frailty, illness, degenerative disease, physical/cognitive/mental disability of end-of-life circumstances" (p. 2). Taking the lead from participants, this guidance uses the term "carer" instead of "caregiver" to better represent the reciprocity within the caring relationships of participants in this study. By pairing "carer" with "unpaid," we are following current shifts away from the usage of "informal" towards more inclusive terminology that recognizes unpaid care provided beyond partners, family, and friends (Stall et al., 2019).

PRINCIPLE #1: RESPECT IDENTITIES AND EXPRESSIONS

The process of coming into and expressing our identities is a highly unique and personal journey that continues to unfold as people grow older. In fact, there is great variation in when and how 2SLGBTQI people come into their various social identities—whether that is one’s sexual orientation, gender identity, and/or gender expression (to name only a few). Regardless of when or how a 2SLGBTQI PLWD comes into their identity or identities, they deserve to be met with kindness and respect whenever these moments of coming out arise.



Gender identity is a person’s innermost sense of their own gender. It is self-determined, and personal – it can include identifying as a woman, a man, both, neither, or somewhere in between.

Gender expression is how we choose to communicate our gender identity to others. This might include emphasizing or deemphasizing certain physical features, clothing, hair style and grooming, language patterns, and other aspects of personal presentation.

It is important to note that a person’s gender expression may not always correspond with their gender identity in the ways we might expect. For example, a person may not have resources to express in the ways they may wish, may feel a need to not express authentically due to safety concerns, or may simply feel comfortable expressing themselves in a particular way.

Regardless of how a person expresses their gender to the world, their gender identity is real and valid.

See our full Components of Human Identity resource at: <https://egale.ca/awareness/the-genderbread-person/>

PRACTICAL EXAMPLES

One of the ways we can ensure we are respectful of identities and expressions is by making a habit of always using inclusive and affirming language, regardless of who you are talking to. For example,

- Use precise terms like Two Spirit, Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, and Intersex, rather than using gay as an umbrella term for all 2SLGBTQI people. Use them regularly in your workplace to challenge silence and stigma.
- Share your pronouns as part of introducing yourself to others. Share them with everyone, not just some people. You don't have to wait for the person you're engaging with to share their pronouns first. In fact, being proactive in sharing your pronouns sends a clear message of allyship.
 - "Hi there, my name is ____, and I use the pronouns _____. Yourself?"
- Regardless of what name or gender marker may appear on a person's official identification documents, always use the chosen name and pronoun they tell you. Confirm if there are any sensitivities around using these details in front of others.
 - "Thank you for sharing your name and pronouns with me. Are there any situations or people with whom you don't want me to refer to you using these details?"
 - "Would you like me to make note of your chosen name and pronouns in your file? I am sensitive to your privacy and want to ensure you are neither outed or misgendered by the other team members."
- When you are not sure about the pronouns someone uses or are addressing a group, it is best to defer to gender neutral pronouns.
 - "**They** are here for a check-up" OR "I just saw **them** a moment ago."
 - Use "Hey **folks**" OR "Good morning, **everyone**" when addressing a group.
- Adopt inclusive and gender-neutral terms. For example, use language that reflects the person's self-described identity and relationships when interacting with someone:
 - "Do you have a **significant other**?"
 - "How long have you and your **partner** been together?"
 - "Tell me about the significant people in your life."
- If you make a mistake with someone's pronouns, simply apologize, correct yourself, and move on. Don't make a fuss or dwell on excuses.

Remember that coming out is a deeply personal process that looks different for everyone. Therefore, it is important to ensure that when you are engaging with patients/clients/residents (e.g., asking about their sexual orientation, gender identity, and/or gender expression), that you do so in a safe, respectful, and confidential manner. In practice, this means following the 2SLGBTQI PLWD's lead and never forcing someone to provide an answer. For example, if the question you posed elicits silence or an uncomfortable response, simply move on.

HELPFUL RESOURCES

For additional information and tips on ways to respectfully engage with 2SLGBTQI PLWD and their primary unpaid carers, check out the following resources:

Recognizing the importance of language

- [The Importance of Language](#)
 - A section of the e-learning module, 2SLGBTQI Identity and Dementia: An Introduction for Healthcare and Social Service Professionals. Egale Canada and the National Institute on Ageing. <https://egale.ca/egale-in-action/2slgbtqi-dementia-care/#learning>
- [Affirming and Inclusive Language](#)
 - A downloadable quick reference sheet. Egale Canada. <https://egale.ca/awareness/affirming-and-inclusive-language/>
- [Pronoun Usage Guide](#)
 - A downloadable quick reference sheet. Egale Canada. <https://egale.ca/awareness/pronoun-usage-guide/>

Checking your assumptions about human identity

- [Four Components of Human Identity](#)
 - A downloadable quick reference sheet. Egale Canada. <https://egale.ca/awareness/the-genderbread-person/>

- Project Implicit
 - Online implicit association tests on a range of topics. Project Implicit. <https://implicit.harvard.edu/implicit/user/demo.canada/ca.static/takeatest.html>
- Support Rainbow Seniors: 3 Things for Service Providers to Know.
 - Infographic. Western University Centre for Research & Education on Violence Against Women & Children. <https://www.vawlearningnetwork.ca/our-work/infographics/supportrainbowseniors/Support-Rainbow-Seniors.pdf>

Navigating changes in identity and relationships

- Navigating Change
 - A section of the e-learning module, 2SLGBTQI Identity and Dementia: An Introduction for Healthcare and Social Service Professionals. Egale Canada and the National Institute on Ageing. <https://egale.ca/egale-in-action/2slgbtqi-dementia-care/#learning>
- Developing Inclusive and Affirming Care for LGBTQ2+ Seniors
 - A downloadable toolkit. Island Health. <https://bccare.ca/wp-content/uploads/2019/07/Inclusive-Care-Toolkit-Island-Health.pdf>
- Creating Authentic Spaces: A Gender Identity and Gender Expression Toolkit to Support the Implementation of Institutional and Social Change
 - A downloadable toolkit. The 519. https://www.the519.org/wp-content/uploads/PDF_Download/519_CASToolkit_ENG_AODA.pdf

PRINCIPLE #2: RECOGNIZE DIVERSE EXPERIENCES OF LIVING AND CARING WITH DEMENTIA

Across the country, our healthcare and social service systems are both rooted in and reinforce long-standing cisheteronormative stereotypes and assumptions that limit understandings and recognition of diverse identities and relationships.

Cisheteronormativity

The cultural and societal bias, often unconscious, that privileges identities and social conventions related to being heterosexual and cisgender, while ignoring or under-representing gender and attraction diversity. This typically includes behaviours that reflect and reinforce the presumption that all people are or ought to be cisgender and heterosexual and should lead their life in ways that reflect such an ideal.

For example, carers may wear several hats. Some they wear every day and others only occasionally. Carers may also find their responsibilities will evolve as they become more comfortable in their role, or as dementia progresses.



Despite calls for change and transformation, these stereotypes and assumptions continue to limit the way we think about and relate to 2SLGBTQI PLWD and their primary unpaid carers; and, subsequently, create barriers that continue to exclude and isolate 2SLGBTQI PLWD and their primary unpaid carers.

PRACTICAL EXAMPLES

If we are to truly recognize the multiple pathways to and diverse experiences of caring, we **cannot** continue to assume that:

- All 2SLGBTQI people (including 2SLGBTQI PLWD and carers) are “out” in all facets of their lives. Be careful never to “out” an 2SLGBTQI patient/client/resident, meaning that if a resident is not open in their sexual orientation or gender identity and they share that with you, be careful not to share that information with others. Sometimes being out can be more dangerous than being closeted.
- A 2SLGBTQI PLWD can be reduced to their sexual orientation, gender identity, gender expression, or diagnosis; rather, people can be many things at the same time. While sexual orientation, gender identity, and gender expression should always be considered in the delivery of their care, so should their ethno-cultural background, race, religion/faith, ability, language, socioeconomic status, and any other relevant factors.

- All 2SLGBTQI people look or act a certain way. There is no template that all 2SLGBTQI PLWD and their primary unpaid carers fit. For example, you cannot “tell” or identify if someone is 2SLGBTQI based on appearances.
- Care relationships or networks align with pre-determined trajectories based upon sexual orientation, gender, racial or ethnic background, age, or other aspects of identity.
- A person living with dementia identifies as 2SLGBTQI that a carer is 2SLGBTQI as well, or vice versa.
- Primary unpaid carers are family members. Primary carers can be friends, acquaintances, or even more distant community members. Their roles as carers are important and need to be recognized.
- That 2SLGBTQI people will feel comfortable accessing your services, even if you signal your inclusivity in visual ways such as putting up a rainbow flag. There are long histories of discrimination against 2SLGBTQI people in healthcare and social services. Efforts to increase inclusivity and safety must be ongoing and intentional.
- Organizations are inherently inclusive or have no 2SLGBTQI patients/clients/residents if none have openly identified this way.

In fact, these “one-size fits all” approaches to care and support perpetuate fear and erasure of 2SLGBTQI identities and caring experiences. It is important to remember that 2SLGBTQI PLWD and their primary unpaid carers bring a wide range of histories into living and caring with dementia. Ultimately, it is up to all of us to open our hearts and minds towards supporting them.

HELPFUL RESOURCES

For additional information and tips on ways to recognize diverse experiences of 2SLGBTQI PLWD and their primary unpaid carers, check out the following resources:

Checking your assumptions about caring relationships

- [A Lifetime of Experiences](#)
 - A section of the e-learning module, *2SLGBTQI Identity and Dementia: An Introduction for Healthcare and Social Service Professionals*. Egale Canada and the National Institute on Ageing: <https://egale.ca/egale-in-action/2slgbtqi-dementia-care/#learning>

- Who are Carers Today?
 - A section of the e-learning module, *2SLGBTQI Identity and Dementia: An Introduction for Healthcare and Social Service Professionals*. Egale Canada and the National Institute on Ageing: <https://egale.ca/egale-in-action/2slgbtqi-dementia-care/#learning>

Recognizing normative systems and structures

- Systems of Oppression and Privilege
 - A downloadable quick reference sheet. Egale Canada: <https://egale.ca/wp-content/uploads/2021/11/Systems-of-Oppression-and-Privilege-Definitions.pdf>

PRINCIPLE #3: SPEAK UP AND STAND IN SOLIDARITY

When working to better support 2SLGBTQI PLWD and their primary unpaid carers, it is important to remember the histories of discrimination and stigmatization that 2SLGBTQI individuals may be carrying with them as they age. These histories (e.g., traumatic experiences with healthcare) may make it more difficult for 2SLGBTQI PLWD and their primary unpaid carers to confront situations of disrespect or intolerance due to imbalances of power and privilege. In these instances of discrimination and barriers to health equity, it is our responsibility to speak up and stand in solidarity with 2SLGBTQI PLWD and their primary unpaid carers.

***A note on rainbows and safer space stickers**

Putting up 2SLGBTQI positive iconography such as flags and stickers are a commitment and a responsibility. Displaying signals of allyship in your space requires both vigilance to actively supporting what these symbols stand for and practicing the necessary humility to understand how you might best support those around you. Stickers should be the last step in creating a safer space.

Additionally, although it is widely recognized in Canada, the rainbow flag is not a symbol of 2SLGBTQI Pride in all countries, and it should not be taken for granted that the image will speak for itself.

PRACTICAL EXAMPLES

Some of the ways that we can stand in solidarity with 2SLGBTQI PLWD and their primary unpaid carers include:

- When you hear stigmatizing language or see homophobic, biphobic, or transphobic behaviour in your organization, challenge it. Hold your colleagues accountable for their actions by calling them into a conversation where you can both listen, learn, and grow.
- Seek consent from your patient/client/resident to communicate context or personal details (e.g., identity, pronouns, relationships, diagnoses) with external organizations and/or service providers when setting up a referral. This can help in making the transition safer and more comfortable. It is important to remember that just because a

2SLGBTQI PLWD or primary unpaid carer came out to you, this does not mean that they are out to everyone.

- Make a conscious effort to spot and address gaps in service provision. Take note of the ways that your organization is:
 - Supporting the needs of a range of 2SLGBTQI identities and caring relationships.
 - Enhancing outside services and programming in ways that reflect the realities of 2SLGBTQI PLWD and their primary unpaid carers.
 - Helping other care providers to also provide affirming care.
- Review your organizational policies and procedures, professional practice, and patient/client/resident resources to ensure explicit inclusion of 2SLGBTQI rights and equity. If your organization does not have EDI (equity, diversity, and inclusion) policies or procedures, speak up and advocate for the changes that will make your organization a more respectful, inclusive, and affirming environment for 2SLGBTQI PLWD and their primary unpaid carers. Some strategies you might consider:
 - Facilitate healthy conversations related to 2SLGBTQI identities, experiences, and families to counter stigma and common misconceptions. For example, encourage ongoing conversations by adding 2SLGBTQI issues as standing agenda items for departmental meetings.
 - Critically consider who is already in the room and who else might need to be in the room during conversations about 2SLGBTQI services and supports.
 - Introduce nongendered washroom options in your building and ensure they are readily accessible (i.e., patients/clients/residents and guests don't need to request a key to access them and are not in distant locations).
 - Conduct a regular Organizational Climate Survey that includes questions to specifically assess 2SLGBTQI safety and inclusion.
 - Review all client-related forms (e.g., registration) and database fields for 2SLGBTQI inclusion, including spaces for pronouns, legal and chosen names, gender list options and honorifics (if applicable).
 - Create staff norms and post these in the staffroom, including best practices for discussing sexual orientation, gender identity, and relationships.
 - Invite a local 2SLGBTQI organization or consultant to provide inclusion training for staff.
 - Create/review a safe or anonymous process for staff and patients/clients/residents to report instances or experiences of discrimination based on sexual orientation, gender identity, and/or gender expression.

- If an anti-2SLGBTQI incident occurs, always follow up with the person(s) impacted to ensure they understand what individual and organizational follow-up has occurred and the types of support they have available to them.
- Maintain confidentiality within the confines of your professional responsibilities. There are certain things like abuse that we cannot keep confidential, but outside of that, make sure patients/clients/residents feel as safe as possible by always keeping what they share in confidentiality.
- Facilitate organization-wide activities or events for [Days of Significance](#) to help raise awareness. Include these in general communication to help create opportunities for discussion and further activism. For example, organize a Pink Shirt Day that focuses on educating about and combatting anti-2SLGBTQI discrimination.

HELPFUL RESOURCES

For additional information and tips on ways to stand in solidarity with 2SLGBTQI PLWD and their primary unpaid carers, check out the following resources:

Acting in allyship

- [Advocating](#)
 - A section of the e-learning module, 2SLGBTQI Identity and Dementia: An Introduction for Healthcare and Social Service Professionals. Egale Canada and the National Institute on Ageing. <https://egale.ca/egale-in-action/2slgbtqi-dementia-care/#learning>
- [How to be an Ally to 2SLGBTQI People Living with Dementia](#)
 - Downloadable resource. Egale Canada. <https://egale.ca/wp-content/uploads/2022/05/2SLGBTQI-Identity-and-Dementia-How-to-be-an-Ally-to-2SLGBTQI-People-Living-with-Dementia-2.0.pdf>
- [Tips on How to Practice 2SLGBTQI Allyship](#)
 - A downloadable quick reference sheet. Egale Canada. <https://egale.ca/awareness/tips-on-how-to-practice-lgbtqi2s-allyship/>
- [Using Person-Centred Language](#)
 - Webpage. Alzheimer Society of Canada. <https://alzheimer.ca/en/take-action/become-dementia-friendly/using-person-centred-language>
- [Inclusive Washrooms](#)
 - Resource. Egale Canada <https://egale.ca/awareness/inclusive-washrooms/>

PRINCIPLE #4: BUILD BRIDGES

The work of creating, enhancing, and/or supporting inclusive and affirming care relationships with 2SLGBTQI PLWD and their primary unpaid carers does not need to be a solo endeavor. When seeking to directly provide wrap-around support and resources for 2SLGBTQI PLWD and their primary unpaid carers, the importance of building connections and relations (or bridges) for enhancing both your own allyship practices and abilities and the care experiences of your patients/clients/residents cannot be understated

PRACTICAL EXAMPLES

Some suggestions that may help you in building connections, and subsequently, developing a trusting and supportive network include:

- Connecting with other practitioners in your organization (or field) who are actively engaging in 2SLGBTQI advocacy and/or have a desire to be stronger allies to 2SLGBTQI communities.
- Talking to other organizations about strategies they have used to become stronger allies to 2SLGBTQI communities.
- Creating communities of practice (or knowledge networks) that include interdisciplinary practitioners and subject matter experts to share best practices, resources, and practical strategies.
- Building referral networks with other affirming practitioners and service providers within dementia care to help ensure 2SLGBTQI PLWD and their primary unpaid carers are receiving respectful and affirming care.
- Building spaces for 2SLGBTQI PLWD and carers to come together, for example in social or support groups.
- Engaging 2SLGBTQI community members and organizations as they have a wealth of expertise and resources.
- Participating in 2SLGBTQI events in your community.

HELPFUL RESOURCES

For additional information and tips on ways to build bridges with and in support of 2SLGBTQI PLWD and their primary unpaid carers, check out the following resources:

Developing networks of support

- [Network Development](#)
 - A section of the e-learning module, 2SLGBTQI Identity and Dementia: An Introduction for Healthcare and Social Service Professionals. Egale Canada and the National Institute on Ageing: <https://egale.ca/egale-in-action/2slgbtqi-dementia-care/#learning>
- [Rainbow Table: Connecting 2SLGBTQI Seniors](#)
 - A virtual space where 2SLGBTQI seniors and allies can connect during the COVID-19 pandemic and beyond. Egale Canada: <https://egale.ca/egale-in-action/rainbowtable/>

PRINCIPLE #5: KEEP LEARNING!

Allyship is an ongoing process of learning and unlearning. To be an active and engaged ally, it is important to do your homework and continue educating yourself. Education is your responsibility, not the responsibility of your 2SLGBTQI patients/clients/residents, colleagues, or friends. This does not mean you should avoid asking them questions about their lives but recognize that not every 2SLGBTQI person is comfortable sharing their story or being an educator for others.

PRACTICAL EXAMPLES

If topics related to the lived experiences of 2SLGBTQ PLWD and their primary unpaid carers are not covered in your training curriculum, take the onus upon yourself to seek out opportunities for continued learning. This may include:

- Keeping up to date on the most recent research and information about the lived experiences and healthcare needs of 2SLGBTQI individuals and communities.
- Reading up on 2SLGBTQI history and allyship practices.
- Checking out films, YouTube channels, and blogs to find out more about 2SLGBTQI people and the issues their communities face.
- Attending 2SLGBTQI cultural events, education sessions, and demonstrations.
- If they are comfortable sharing, making time to speak with your 2SLGBTQI family, friends, and colleagues to learn about their experiences.

HELPFUL RESOURCES

For additional information and continued learning related to the lived experiences of 2SLGBTQI PLWD and their primary unpaid carers, check out the following resources:

2SLGBTQI identities and experiences

- [National Resource Centre on 2SLGBTQI Aging](#)
 - An online storehouse of information focused on the lived experiences of 2SLGBTQI older adults and aging issues in Canada. Egale Canada and the National Institute on Ageing. <https://2slgbtqi-aging.ca>

- Canadian Queer History Timeline
 - A digital exhibition of 2SLGBTQI history. Queer Events. <https://www.queerevents.ca/queer-history/canadian-history-timeline>
- Fix Hearts, Not Parts
 - Intersex awareness resources. Egale Canada. <https://egale.ca/egale-in-action/intersex-awareness-day/>
- Inqueery
 - Video series on the history and meaning of various 2SLGBTQI identity terms. Them. <https://www.them.us/video/series/inqueery>
- Two Spirits, One Voice
 - Mini-documentary (duration: 16:28). Egale Canada. <https://youtu.be/t8XUCuuJPCc>

Patient/Client rights and equity

- Dementia & Advance Care Planning: Context and Considerations for 2SLGBTQI Communities
 - Community Conversations brief. Egale Canada. <https://egale.ca/awareness/dementia-advanced-care-planning-session-new-horizons-brief/>
- Elder Abuse in Our LGBTQ Community: An Intervention Guide for Service Providers and Partners in Care
 - A downloadable resource. Elder Abuse Prevention Ontario. <https://eapon.ca/wp-content/uploads/2018/08/EAPO-Elder-Abuse-in-our-LGBTQ-Community-Training-Module-EN.pdf>
- Two-Spirit and LGBTQ+ Canadian Healthcare Bill of Rights
 - Downloadable booklet. Canadian Virtual Hospice. <https://www.virtualhospice.ca/2SLGBTQ/media/q1yb5410/bill-of-rights.pdf>
- RNAO Best Practices Guidelines: Promoting 2SLGBTQI+ Health Equity
 - Consensus paper. Registered Nurses Association of Ontario. https://rnao.ca/sites/rnao-ca/files/bpg/2SLGBTQI_BPG_June_2021.pdf

- [The Canadian Charter of Rights for People with Dementia](#)
 - Webpage. Alzheimer Society of Canada. <https://alzheimer.ca/en/take-action/change-minds/canadian-charter-rights-people-dementia>
- [Leading & Learning with Pride](#)
 - A downloadable toolkit on supporting 2SLGBTQI+ seniors. City of Toronto Seniors Services and Long-Term Care. <https://www.toronto.ca/wp-content/uploads/2022/06/988a-leading-learning-toolkit-digital.pdf>
- [2SLGBTQI+ Resources](#)
 - Resource page. Ontario Centres for Learning, Research and Innovation in Long-Term Care. <https://clri-ltc.ca/lgbtq/>
- [Leaving No One Behind in Long-Term Care: Enhancing Socio-Demographic Data Collection in Long-Term Care Settings](#)
 - White paper report. National Institute on Ageing and Wellesley Institute. <https://static1.squarespace.com/static/5c2fa7b03917eed9b5a436d8/t/62012044f0158e27b04f2880/1644240964901/LeavingNoOneBehind.pdf>

SELECT RESEARCH

For additional information and continued learning related to the lived experiences of 2SLGBTQI PLWD and their primary unpaid carers, check out the following research reports and journal articles:

Directly related to 2SLGBTQI issues and dementia

- **6** [Coming Out and Coming in to Living with Dementia: Enhancing Support for 2SLGBTQI People Living with Dementia and Their Primary Unpaid Carers](#)
 - Research report. Egale Canada. https://egale.ca/wp-content/uploads/2022/04/NIA_EGALE_MAY12_EN.pdf
- [Lesbian, Gay, Bisexual and Trans* Individuals Living with Dementia: Concepts, practice and rights](#)
 - Edited book. Taylor & Francis Group. <https://www.taylorfrancis.com/books/edit/10.4324/9781315732718/lesbian-gay-bisexual-trans-individuals-living-dementia-sue-westwood-elizabeth-price?refId=233c75bf-e17e-402c-8698-910126b6bc13&context=ubx>

- **6** Cognitive Impairment, Alzheimer’s Disease, and Other Dementias in the Lives of Lesbian, Gay, Bisexual and Transgender (LGBT) Older Adults and Their Caregivers: Needs and Competencies
 - Academic paper. Journal of Applied Gerontology. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5383534/>
- Transing dementia: Rethinking compulsory biographical continuity through the theorization of cisism and cisnormativity
 - Academic paper. Journal of Aging Studies. <https://memoryfriendly.org.uk/wp-content/uploads/2021/08/Transing-dementia-Rethinking-compulsory-biographical-continuity-Silverman-Baril-2021.pdf>

Healthcare access

- **6** LGBTQ+ Aging Research in Canada: A 30-Year Scoping Review of the Literature
 - Academic paper. <https://www.mdpi.com/2308-3417/6/2/60>
- **6** A Framework for Enhancing Access to Equitable Home Care for 2SLGBTQ+ Communities
 - Academic paper. International Journal of Environment Research and Public Health. <https://www.mdpi.com/1660-4601/17/20/7533>
- Care and LGBT Aging in Canada: A Focus Group Study on the Educational Gaps among Care Workers
 - Academic paper. Clinical Gerontologist. <https://www.tandfonline.com/doi/full/10.1080/07317115.2018.1544955?scroll=top&needAccess=true>

End-of-life and advanced care planning

- **6** End-of-Life Preparations Among LGBT Older Adults
 - Academic paper. Generations: Journal of the American Society on Aging. <https://www.sfu.ca/content/dam/sfu/lgbteol/pdf/End%20of%20life%20preparations%20deVries%20%26%20Gutman%20Generations%202016%20article.pdf>
- **6** Forgotten Wishes: End-of-life Documents for Trans People with Dementia at the Margins of Legal Change
 - Academic paper. Canadian Journal of Law and Society. <https://www.cambridge.org/core/services/aop-cambridge-core/content/view/5265D12FAFD58C0A846A5CB2BAE5564E/S0829320120000137a.pdf/forgotten->

[wishes-end-of-life-documents-for-trans-people-with-dementia-at-the-margins-of-legal-change.pdf](#)

- [Later Life Care Planning and Concerns of Transgender Older Adults in Canada](#)
 - Academic paper. The International Journal of Aging and Human Development. <https://www.sfu.ca/content/dam/sfu/lgbteol/pdf/Pang%20Later%20Life%20Planning%20Transgender%20Older%20Canadians.pdf>
- [Advance Care Planning Among Older LGBT Canadians: Heteronormative Influences](#)
 - Academic paper. Sexualities. <https://journals.sagepub.com/doi/abs/10.1177/1363460719896968>

CONCLUSION

In summary, these guiding principles are rooted in the findings from [Coming Out and Coming In to Living with Dementia](#), a national qualitative research study that engaged 2SLGBTQI community members living with dementia, primary unpaid carers of 2SLGBTQI PLWD, and community group representatives and dementia care and service provider stakeholders. They also build from other current available research, existing relevant best practices and guidance, and expert opinion.

Each section has shared a key principle, along with practical examples and helpful resources, for providing affirming and inclusive care to 2SLGBTQI PLWD and their primary unpaid carers. As a reminder the five key principles are:

1. Respect identities and expressions
2. Recognize diverse carers
3. Speak up
4. Build bridges
5. Keep learning

As you move forward, we encourage you to continue building on these guidelines—keep learning, connecting with other allies and local community organizations, and finding ways to help others to also foster more equitable dementia-care services for 2SLGBTQI people and their communities.

This is just the beginning!

Egale

NIA NATIONAL
INSTITUTE
ON AGEING 