

# COMING OUT AND COMING IN TO LIVING WITH DEMENTIA:

Enhancing Support for 2SLGBTQI  
People Living with Dementia and  
their Primary Unpaid Carers

Executive Summary | May 2022

**Egale**

**NIA** NATIONAL  
INSTITUTE  
ON AGEING 

# 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.

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# EXECUTIVE SUMMARY

What are the unique experiences and needs of Two Spirit, lesbian, gay, bisexual, transgender, 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, in 2019 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. Funded by a Public Health Agency of Canada (PHAC) Dementia Community Investment Grant, this research study is the first phase in a multi-phase research, education, and awareness project. With future project phases in mind, we designed the research with a primary focus to expand knowledge and understanding, spark critical conversations, and create collaborations towards better supporting 2SLGBTQI people living with dementia (PLWD) and their primary unpaid carers across Canada.

In this report, Egale and NIA share the findings from their 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. We situate our discussion of dementia and unpaid care in a current climate of growing and broad-based attention to the need to improve Canada's healthcare systems and structures especially for aging populations, amidst increased reliance on the labour of unpaid carers, and as part of re-emerging conversations about the dynamics and distribution of care work. We also situate this discussion as part of an ongoing recognition of the need to expand care and support services that can better meet the needs of 2SLGBTQI and other equity-deserving communities, with a particular focus on living and caring in the context of dementia.

## KEY FINDINGS

**Becoming Carers:** People can become primary unpaid carers for 2SLGBTQI PLWD through a wide variety of pathways and from a range of prior positions, including close pre-existing relationships (e.g., as spouses, close family members, and close friends) and more distant prior relationships (e.g., acquaintance, fellow community members). Carer participants discussed their journeys into care in different ways, including from a strong sense of identity as a carer, pragmatic rationale, and circumstantial factors, and shared insights into how they brought previous experiences of providing care into their current caring practices and roles. There is a need to expand beyond a focus on spousal and children carers and improve carer supports if 2SLGBTQI PLWD and their carers are to be better supported, along with a need for increased recognition of the gendered dimensions of unpaid care labour and of the diverse experiences and expertise that carers bring to their practices and roles.

**Coming Out and Coming in to Living with Dementia:** Regarding the significance of gender and sexual identity in experiences of living with dementia and providing care, the concept of change emerged centrally as participants described their experiences of grappling with dementia diagnoses and the impact of dementia on their abilities, relationships, and how they were recognized and treated. Some participants drew parallels between the changes they experience while coming into living with dementia and the relationship changes that many 2SLGBTQI people have experienced in response to coming out about their sexual and/or gender identity. Enhancing supports for grappling with change in caring relationships, recognizing the multiplicity and fluidity of identities, and offering a spectrum of services (e.g., from aging in place to community living and long-term care options) would benefit 2SLGBTQI people living with dementia and carers alike.

**The Power of Support Networks:** 2SLGBTQI PLWD and carers participants sought support from a range of sources including family and friends, community members and groups, and healthcare and social services. These participants reflected on what was working well and where options for support fell short: including in the coming together of family and friends to the falling away of acquaintances and lack of support networks, and experiences of findings support and inclusion in formal care services and encountering barriers to access. Key next steps that emerged from these participants reflections, as well as observations by 2SLGBTQI community group representatives and dementia care and aging service providers, included breaking down silos between dementia-specific and 2SLGBTQI-focused support, enhancing the availability and accessibility of care and support resources, and increasing understanding and awareness of the unique needs of 2SLGBTQI PLWD among communities and care services.

## RECOMMENDATIONS

Rooted in the findings of our study, we provide the following recommendations to better enable programming, policy, advocacy, and research:

- **Build 2SLGBTQI-inclusive dementia-related services and community spaces**, including integrating discussions about dementia into existing 2SLGBTQI support and social groups and creating more opportunities for 2SLGBTQI PLWD to come together in support and community.
- **Increase recognition and support for primary unpaid carers of 2SLGBTQI PLWD**, including through increasing recognition of diversely situated primary unpaid carers in workplace and government care policies and leaves, and creating dedicated spaces such as support groups for primary unpaid carers of 2SLGBTQI PLWD.
- **Enhance supports for 2SLGBTQI communities and carers through structural and systems-level change**, including by reducing barriers to accessing dementia-related care in rural and small-town communities, and integrating 2SLGBTQI histories and experiences into core course content for healthcare and social service provider training across a range of professions.
- **Broaden perspectives and deepen community engagement for future critical research**, including through building rapport, trust, and accountability in relationship with 2SLGBTQI communities and community members, examining the particularities of living in suburban, rural, and remote areas for access to services and networks of support, and intentionally welcoming and learning from Indigenous, Black, and racialized 2SLGBTQI people who are living with dementia.

While these recommendations are focused on 2SLGBTQI communities and carers, they also speak to broad social and structural issues including healthcare and social service gaps that, if addressed, could be of potential benefit to many groups.

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