



Dementia & Advance Care Planning:

Context and Considerations for 2SLGBTQI Communities



Community Conversations Brief



Acknowledgements

About Egale Canada

Egale is Canada's leading organization for 2SLGBTQI people and issues. We improve and save lives through research, education, awareness, and by advocating for human rights and equality in Canada and around the world. Our work helps create societies and systems that reflect the universal truth that all persons are equal and none is other.

Acknowledgements

Authors & Contributors

Celeste Pang, PhD, Egale Canada

Krista James, National Director, Canadian Centre for Elder Law

Advisory Committee Members

Bruce Cameron, Gay and Grey Montreal

Cheryl Loadman, Queer Seniors of Saskatchewan

Julien Rougerie, Fondation Emergence

Melanie Smith, Dixon Hall Neighbourhood Services

Thank you to all staff who supported the Community Conversations Sessions, and all community members who participated in them.

Publishing Date

March 1, 2022

© Egale Canada 2022

Version française disponible.

Funded by the Government of Canada



Contents

Acknowledgements 2

Framing the Issue 5

The Community Conversations Session 8

Supported Decision-Making and Substitute Decision-Makers 11

Questions to Explore During Advance Care Planning.....13

Additional Resources14

References16

Framing the Issue

Advance care planning (ACP) is a process that involves:

1. Clarifying our values and wishes for health and personal care; and
2. Implementing strategies to help ensure our values and wishes are respected.

For most people ACP has multiple steps and can take time. Roughly speaking, ACP involves:

- **Reflecting on what matters:** Generally, ACP starts with thinking about our values, beliefs and wishes for health and personal care. For some people this is a very social activity; for others, this work is private, or might involve counseling or professional guidance.
- **Talking about our values and wishes:** Effective ACP involves telling others about our values and wishes so that they are better able to understand and honour them. Typically, it is useful to inform at least one close friend or family member, as well as key health care providers.
- **Choosing a substitute decision-maker (SDM):** Every province and territory in Canada (other than Nunavut) has legislation that allows adults to designate a person to make health or personal care decisions for them at times when they cannot make them for themselves, for example, due to progression of an illness or disease. Legally appointing a SDM provides reassurance that the person you trust most will guide your care. If you do not choose a SDM, then health care providers will likely choose for you, and family and friends may argue over who makes your care decisions.
- **Documenting values, beliefs and wishes:** SDMs should follow the person's previously expressed wishes, where reasonable. Documentation of wishes makes it easier for SDMs to fulfill their responsibilities.

Advance care planning helps us to:

- Have more control over what kind of care we receive;
- Make difficult decisions about care with greater confidence and more support;
- Feel more hope and safety about receiving health care;
- Support the people we love when they must confront our suffering or death; and
- Minimize family and friend conflict over our health and end of life care.



Generally, advance care planning is about choosing the person you most trust and letting them know about your values and wishes, not making health care decisions in advance. Some provincial and territorial laws allow adults to decline or accept very specific treatment in advance. These tools are not very reliable because it is difficult to predict the precise health circumstances we will face and health care providers have to make sure that consent to any health care treatment is informed (James, 2022). Written advance directives (previously called living wills) are best suited to people who have a specific diagnosis and can anticipate the care they might be offered in a short and predictable period of time. For most of us it is impossible to predict all the factors that could impact our health care treatment options (James, 2022).

The benefits of advanced care planning extend to 2SLGBTQI communities, with specific nuances and considerations. Research on advanced care planning within 2SLGBTQI communities and in relation to dementia in 2SLGBTQI communities is limited, while there has been some critical attention paid in recent years. For example, one recent study engaged older gay men living with HIV in Montreal to learn more their experiences and perspectives and how to improve access and uptake of advance care planning (Dube et al., 2021). Among the unique considerations found was that isolation among participants was a barrier to engagement in end-of-life care discussions and planning, and that uncertainty about disclosure (of sexual orientation, HIV status, or both) was a source of tension and challenge for many participants in considering advanced care planning (Dube et al., 2021).

One national qualitative study focused on later and end-of-life care planning among LGBT older adults in Canada similarly identified interpersonal challenges to having advance care planning conversations (de Vries et al., 2019). This study also found that formal document completion (e.g., of an advance care plan) was a significant obstacle for some participants' advance care planning, while for others it was a motivator (de Vries et al., 2019). Ambivalent ties with families of origin, the strengths and challenges of ties with chosen family, and experiences of isolation and lack of trust impacted many participants' approaches to later and end-of-life preparations (de Vries et al., 2019). An analysis of focus groups and interviews with trans identified older adults who participated in this study found specific facilitators and barriers to later and end-of-life care planning, including the impact of economic precariousness and meeting immediate needs precluding long-term planning for the future (Pang, Gutman, and de Vries, 2019). Together, this research emphasized the need to support and encourage more conversations about advance care planning, and the need to better understand and address barriers and facilitators for LGBT older adults to later and end-of-life care

planning (de Vries et al., 2019; Pang, Gutman, and de Vries, 2019). Bringing into consideration living with dementia as a 2SLGBTQI person and the many changes and care encounters that may take place adds another layer to the important role that advance care planning can play (see Flanagan and Pang, forthcoming).

The Community Conversations Session

On January 26th, 2022, Egale Canada hosted a virtual *Community Conversations for 2SLGBTQI Seniors: Focus on Dementia and Advance Care Planning* session. The session brought together 2SLGBTQI older adults, advisory committee members, and a guest expert to share knowledge, experiences, and ideas. The session included two components: a presentation by a guest expert, and breakout room discussions.

The guest expert for this session was Krista James, lawyer and National Director at the Canadian Centre for Elder Law. Krista's presentation, *Dementia and Advance Health Care Planning* focused on understanding advance care planning and healthcare decision-making rights, the implications of a dementia diagnosis, and steps individuals can take to prepare an advance care plan. The presentation foregrounded how people living with dementia can still make decisions about their health and personal care, including making the decision to refuse care or to live with risk. It highlighted how a person's decision-making may change along the dementia journey, moving and shifting from independent decision-making, decision-making with communication assistance, decision-making with support from trusted people, and decision-making by a substitute decision-maker. Building on this presentation, two guidance sheets can be found below, on **Supported Decision-Making and Substitute Decision-Makers** and **Questions to Explore During Advance Care Planning**.

In the breakout room discussions, participants discussed issues of dementia and advance care planning in 2SLGBTQI communities together, building on the knowledge shared in the guest presentation and their own observations and lived experiences. The discussions were facilitated by project advisory group members. Two prompts guided the discussion about dementia and advance care planning:

- What are the challenges you see for 2SLGBTQI communities?
- How can service providers and policy makers greater support 2SLGBTQI communities?

Participants' ideas, observations, experiences, and perspectives shed light on key considerations for 2SLGBTQI people considering advance care planning and the implications of living with dementia. Key themes and points from participants' discussions in the breakout rooms included:



Finding trusted others and choosing attorneys for personal care: Finding someone who is trusted and who can understand and speak on one's behalf as an attorney for personal care can be very difficult. There is isolation in 2SLGBTQI communities, and there is also isolation within families. Having more immediate family and community can provide more opportunities to identify a trusted advocate or representative; at the same time, navigating relationships with close others and family members can be challenging and cause complications when it comes to supported and substitute decision-making. While others may be well-meaning, relationships can become challenging in difficult circumstances and when it comes to the details of making health and personal care decisions. Potential attorneys for personal care must be well-vetted and also be capable of representing a person's values and wishes while potentially managing a myriad of family members (including families of origin and choice) who may have conflicting ideas about decisions.

Intergenerational support: Having younger people as advocates for elders can be hugely beneficial. Intergenerational support is very important, especially for 2SLGBTQI older adults who are single and/or who may not have children who are there to step-up to advocate, including as supportive or substitute decision-makers.

Treating people living with dementia as human beings: People with dementia may already be treated as if they are lacking as people, and not treated as full citizens. With homophobia, transphobia, and other layered forms of oppression this can be exacerbated for 2SLGBTQI people living with dementia. Care workers and others must be reminded that people living with dementia are full human beings, who continue to deserve recognition and respect.

Dementia and trauma: Being 2SLGBTQI and living with dementia, people may experience a harkening back to experiences of homophobia and/or transphobia, and potential re-traumatization. Many 2SLGBTQI older adults today have experienced harm, including harm from medical institutions. For example, some 2SLGBTQI people have experienced electro-shock therapy and institutionalization. Care providers and others must be aware of 2SLGBTQI communities' histories and in turn the lived experiences that individuals may have had, as negative experiences from the past may resurface with memory loss and other symptoms of dementia. In turn, education and training is needed that goes beyond basics and focuses on how dementia and dementia care may differently impact 2SLGBTQI community members.



Education and training: Increased education about 2SLGBTQI older adults' issues must be shared in education institutions, and continuously in relevant workplaces. Healthcare professionals must be trained and prepared to treat 2SLGBTQI older adults with dignity and respect, respecting their choices and respect those people they have chosen to make decisions on their behalf. This includes, for example, training in nursing schools. This should not just be the lip-service of “box-checking”: there must be thorough education and follow-up with students and workers to ensure good care. In long-term care, there is a particular challenge of staff turnover, and educating and training staff must thus be an ongoing effort. Diversity training and policy should be implemented in all care facilities. There currently is not enough diversity education and training, and personal judgements too often come into play to the detriment of 2SLGBTQI older adults.

Systemic challenges and opportunities: There is not a one-size-fits-all approach. Greater knowledge about dementia and advance care planning, and about 2SLGBTQI community members' experiences, wishes, and needs must be transmitted so that others (including care providers, fellow community members, society at large) can be more responsive. At the same time, our healthcare and social systems are overwhelmed and people do not necessarily have the time to deeply consider and implement more inclusive processes into their work—and this is a systemic problem. Many people especially in rural areas are already under-served medically, with no family doctors, long wait times for assessments and appointments, and no easy access to 2SLGBTQI inclusive or dementia focused care. There should be more funding for support groups for 2SLGBTQI older adults and communities, and funding to create tools to connect people to appropriate support and services. Long-term care in particular would benefit from provincial and territorial ombudspersons, who as part of their role could specifically address 2SLGBTQI communities' concerns. Policy is not practice—there are many gaps to be filled.

In summary, participant discussions emphasized the need for greater attention to the particularities of 2SLGBTQI communities' experiences, needs, and concerns when it comes to advance care planning and dementia, and to related realms of long-term care, general healthcare access and equity, and community and intergenerational support. Increasing education in communities and for care providers, recognizing distinct experiences, and tackling systemic barriers to inclusive and equitable care is also needed.

Supported Decision-Making and Substitute Decision-Makers

Substitute decision-makers are needed when a person cannot make their own decision. Physicians and other health care providers can only make health care treatment decisions in emergency situations. Otherwise, informed consent is required (James, 2022).

Unless a person has a court-appointed guardian, a health care provider must attempt to get informed consent from the person who requires care. Some people with disabilities, such as people living with dementia, cannot make certain decisions independently, but they may be able to make the decision if they have support from people they trust. A supportive decision-maker could be a friend or family member. They can help by providing whatever assistance is welcome (James, 2022). This includes:



Taking notes at appointments



Researching medications



Explaining things in simple language



Booking language interpreters



Listening when the other person needs to talk



Asking helpful questions



Helping the person prepare for the appointment



Dementia can be a disability, and healthcare providers must accommodate disability. Health care providers must communicate with people in a manner appropriate to their skills and abilities. For some people this means welcoming the supportive decision-maker into discussions about care (James, 2022).

If a person cannot understand the information relevant to a decision even if they have support, they will require a substitute decision-maker. The advance care planning process allows an adult to choose their substitute decision-maker for health care in advance.

In choosing someone to be a substitute decision-maker, there are a number of considerations to take into account. The Canadian Centre for Elder Law recommends you choose someone who:

- ✓ Knows you well
- ✓ Listens to you and respects your wishes
- ✓ Will speak with you about your needs & wishes
- ✓ Is comfortable communicating with healthcare professionals
- ✓ Will advocate for what you would want

Questions to Explore During Advance Care Planning

Advance care planning is a process. This process includes thinking about your values, beliefs and wishes for health and personal care, and speaking about them with others. Below is a set of questions that you can explore during advance care planning, and in relation to end-of-life care (from James, 2022).

- What therapies have supported you in the past?
- What brings you comfort during difficult times?
- How do you feel about pain and suffering?
- How important is it for you to maintain your ability to think clearly?
- How important to you is privacy?
- What things give your life more meaning?
- What brings you joy?
- What are your fears about death, illness or pain?
- Who would you want to spend time with if you were very ill or dying?
- Under what circumstances would you want to be allowed to die?
- What would a good death look like to you?
- Would you like to donate your organs following your death?

Additional Resources

Below is a list of additional resources that may be of interest to 2SLGBTQI communities and service providers for further learning about advance care planning. The included resources are Canadian-based, while the academic journal articles include research from Canadian, the USA, and the UK.

Advance care planning resources:

- My Speak Up Plan. Advance Care Planning Canada. *Advance care planning online interactive workbooks*. <https://www.advancecareplanning.ca/my-plan/>
- Living Well, Planning Well: An Advance Care Planning Resource for Accessing Your Rights. Canadian Hospice Palliative Care Association and the BC Centre for Palliative Care. *This 2021 resource includes regional summaries about legal documents and decision-making across provinces and territories*. <https://www.advancecareplanning.ca/wp-content/uploads/2020/06/Speak-Up-Public-Workbook-ENG-2.pdf>
- Advanced Care Planning Across Canada. Canadian Virtual Hospice. *Includes links to resources hosted by provincial and territorial governments, as available*. https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Decisions/Advance+Care+Planning+Across+Canada.aspx
- My Voice—Expressing My Wishes for Future Health Care Treatment. Advanced Care Planning Guide. British Columbia, Ministry of Health. <https://www.health.gov.bc.ca/library/publications/year/2020/MyVoice-AdvanceCarePlanningGuide.pdf>

Academic journal articles:

*indicates open access

- de Vries, B., Gutman, G., Humble, Á., Gahagan, J., Chamberland, L., Aubert, P., Fast, J., & Mock, S. (2019). End-of-Life Preparations Among LGBT Older Canadian Adults: The Missing Conversations. *International Journal of Aging & Human Development*, 88(4), 358–379. <https://doi.org/10.1177/0091415019836738>
- de Vries, B., Gutman, G., Soheilipour, S., Gahagan, J., Humble, Á., Mock, S., & Chamberland, L. (2020). Advance care planning among older LGBT Canadians: Heteronormative influences. *Sexualities*, 136346071989696–. <https://doi.org/10.1177/1363460719896968>

- *Di Lorito, C., Bosco, A., Peel, E., Hinchliff, S., Denning, T., Calasanti, T., de Vries, B., Cutler, N., Fredriksen-Goldsen, K. I., & Harwood, R. H. 2021. Are dementia services and support organisations meeting the needs of Lesbian, Gay, Bisexual and Transgender (LGBT) caregivers of LGBT people living with dementia? A scoping review of the literature. *Aging & Mental Health*, (ahead-of-print), 1–10. <https://doi.org/10.1080/13607863.2021.2008870>
- Dube, D., Sussman, T., Brotman, S., de Vries, B., & Gutman, G. (2021). Advance Care Planning among Older Gay Men Living with HIV in Montreal, Canada: Challenges to Thinking and Talking about Future Care. *Journal of Homosexuality*, (ahead-of-print), 1–17. <https://doi.org/10.1080/00918369.2020.1855029>
- Fredriksen-Goldsen, K. I., Jen, S., Bryan, A. E. B., & Goldsen, J. (2018). 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. *Journal of Applied Gerontology*, 37(5), 545–569. <https://doi.org/10.1177/0733464816672047>
- Pang, C., Gutman, G., & de Vries, B. (2019). Later Life Care Planning and Concerns of Transgender Older Adults in Canada. *The International Journal of Aging and Human Development*, 89(1), 39–56.

Legal clinics and resource centres:

- Canadian Centre for Elder Law (CCEL). CCEL works collaboratively with community stakeholders, provincial agencies, national bodies and other organizations to uncover hidden issues that dramatically affect older adults. <https://www.bcli.org/sectors/ccel/>
- Advocacy Centre for the Elderly (ACE). ACE is a community based legal clinic for low income senior citizens that provides direct legal services to low-income seniors, based in Toronto. They also engage in public legal education and law reform activities. <http://www.advocacycentreelderly.org/>
- Public Legal Education Association of Saskatchewan (PLEA). PLEA is a non-profit, non-government organization that exists to educate, inform and empower through law-related education. Their resources include resources related to health, advance care planning, and for older adults. <https://www.plea.org/>

References

- de Vries, B., Gutman, G., Humble, Á., Gahagan, J., Chamberland, L., Aubert, P., Fast, J., & Mock, S. (2019). End-of-Life Preparations Among LGBT Older Canadian Adults: The Missing Conversations. *International Journal of Aging & Human Development*, 88(4), 358–379. <https://doi.org/10.1177/0091415019836738>
- Dube, D., Sussman, T., Brotman, S., de Vries, B., & Gutman, G. (2021). Advance Care Planning among Older Gay Men Living with HIV in Montreal, Canada: Challenges to Thinking and Talking about Future Care. *Journal of Homosexuality*, (ahead-of-print), 1–17. <https://doi.org/10.1080/00918369.2020.1855029>
- Flanagan and Pang (forthcoming, 2022). Coming Out and Coming In to Living with Dementia: Enhancing Support for 2SLGBTQI People Living with Dementia and their Primary Unpaid Carers. Egale Canada.
- James, Krista. (2022). *Dementia and Advance Healthcare Planning* [Virtual public presentation]. Community Conversations with 2SLGBTQI Older Adults: Focus on Dementia and Advance Care Planning, Egale Canada.
- Pang, C., Gutman, G., & de Vries, B. (2019). Later Life Care Planning and Concerns of Transgender Older Adults in Canada. *The International Journal of Aging and Human Development*, 89(1), 39–56. <https://doi.org/10.1177/0091415019843520>

Egale



Suite 217-120 Carlton Street,
Toronto, ON. M5A 4K2



(416) 964-7887



research@egale.ca



egale.ca