BC Centre for
Palliative Care

Facilitating Equitable Access to Palliative and End-Of-Life Care for Underserved Populations in British Columbia: Knowledge Exchange Series (2025)

Insights Specific to:

People Living with Dementia

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For More Information

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Knowledge Exchange Overview

In Spring 2025, the BC Centre for Palliative Care on behalf of the BC Palliative Care Research Collaborative hosted a three-part virtual **Knowledge Exchange Series** on *facilitating equitable access to palliative and end-of-life care for underserved populations in BC*.

Shaped by research, expert insights, and lived experiences, the series aimed to advance an equity-informed approach to palliative care by sharing stories, highlighting promising practices, strengthening connections between health and community systems, and identifying future directions for policy, practice, and research.

Discussions and activities focused on twelve underserved population groups with limited access to essential palliative and end-of life care services.

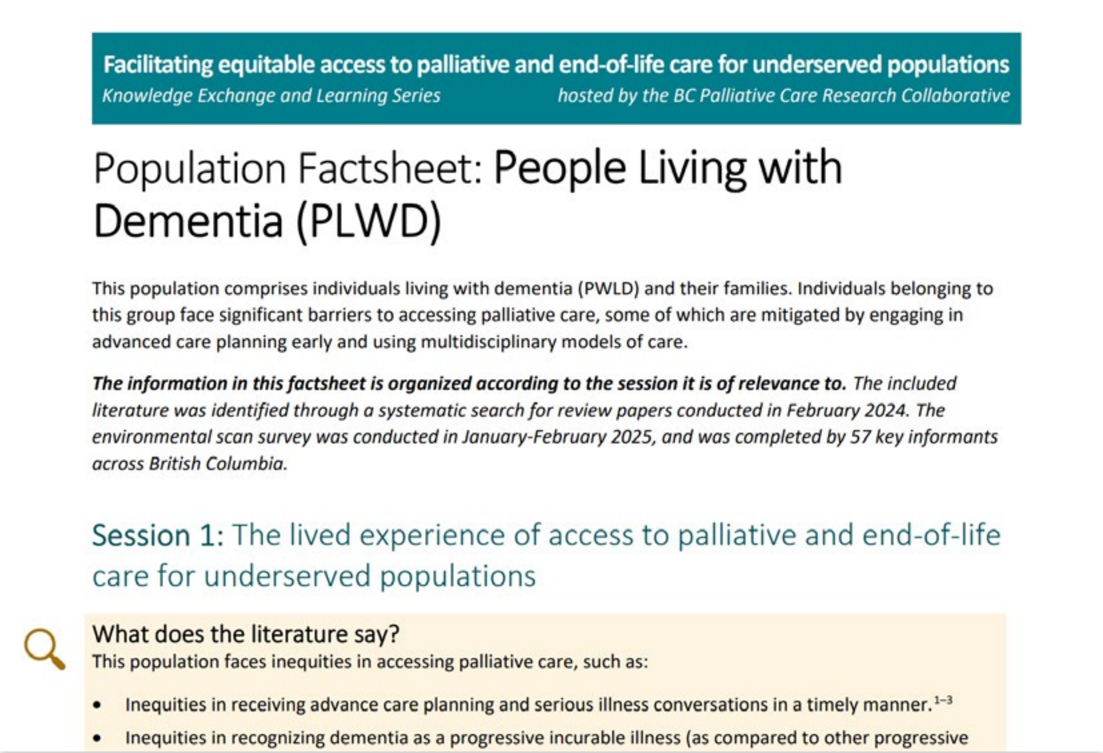
Read the full Summary Report here.

Insights Specific to People Living with Dementia

Insights from the Literature and Key Informants

To inform discussions about **people living with dementia** during the Knowledge Exchange sessions, a population fact sheet was developed. The fact sheet summarizes key themes from a literature review and insights gathered from key informants through an online survey—highlighting experiences, opportunities, facilitators, and barriers to care.

View the population fact sheet here. A preview is shown below.



Facilitating equitable access to palliative and end-of-life care for underserved populations
Knowledge Exchange and Learning Series *hosted by the BC Palliative Care Research Collaborative*

Population Factsheet: **People Living with Dementia (PLWD)**

This population comprises individuals living with dementia (PWLD) and their families. Individuals belonging to this group face significant barriers to accessing palliative care, some of which are mitigated by engaging in advanced care planning early and using multidisciplinary models of care.

The information in this factsheet is organized according to the session it is of relevance to. *The included literature was identified through a systematic search for review papers conducted in February 2024. The environmental scan survey was conducted in January-February 2025, and was completed by 57 key informants across British Columbia.*

Session 1: The lived experience of access to palliative and end-of-life care for underserved populations

What does the literature say?
This population faces inequities in accessing palliative care, such as:

- Inequities in receiving advance care planning and serious illness conversations in a timely manner.[1–3]
- Inequities in recognizing dementia as a progressive incurable illness (as compared to other progressive

Insights from the Knowledge Exchange Series

Key barriers, potential solutions and recommended actions that emerged from discussions on improving palliative and end-of-life care access for *people living with dementia.*

Insights Specific to People Living with Dementia

Barriers

- **Limited caregiver support:** Caregivers often lack education on available services. High costs and complex access processes can deter use of respite care.
- **Difficult system navigation:** Families struggle to understand care options and transitions (for example, understanding what kind of care is needed and when it may be time to transition to a different level of support). Dementia care is often overlooked in hospice settings.
- **Lack of advance care planning:** Many are unfamiliar with the process, leading to confusion and conflict during critical times.
- **Rigid care models:** Dementia doesn't follow a predictable path, making standard clinical tools and models less effective. We need to develop models and interventions that adapt to people, rather than try to fit people into existing models.
- **Unfriendly environments:** Care settings are often not designed for people with dementia or to support family involvement. For example, hospices are often designed to feel cozy but are not necessarily designed to be dementia-friendly.

Solutions

- **Improve respite access:** Reduce costs, simplify access, and increase public investment to ensure equitable caregiver support.
- **Design safe, calming spaces** that protect families against sensory overload, noise, chaos or clutter and bring care to the patient, wherever they are.
- **Involve caregivers in planning** and make resources more visible. For those without family, find alternative support.
- **Use transition providers** to maintain continuity, reduce confusion, and ease the emotional strain of having to retell their story at every step of their care journey.
- **Expand caregiver education** using tools like death doula training, online resources, and dedicated dementia educators.
- **Promote advance care planning,** especially for younger patients. Include cultural and spiritual values in these discussions.
- **Relax hospice criteria** to better match real needs and improve access to care.

Recommended Action

As more people are cared for at home, there is a need to support caregivers. Caregivers often lack the knowledge and guidance they need when entering this role, and many are unaware of the services available to them. One-on-one education and emotional support are essential to help caregivers navigate resources, care for themselves, and maintain quality of life for all involved. Respite beds and safe care spaces offer essential relief and a place for caregivers to process the emotional weight of caregiving. While the healthcare system plays a role, much of the responsibility falls on those outside of formal care settings, making community-based support and education even more important.

Insights from the Knowledge Exchange Series

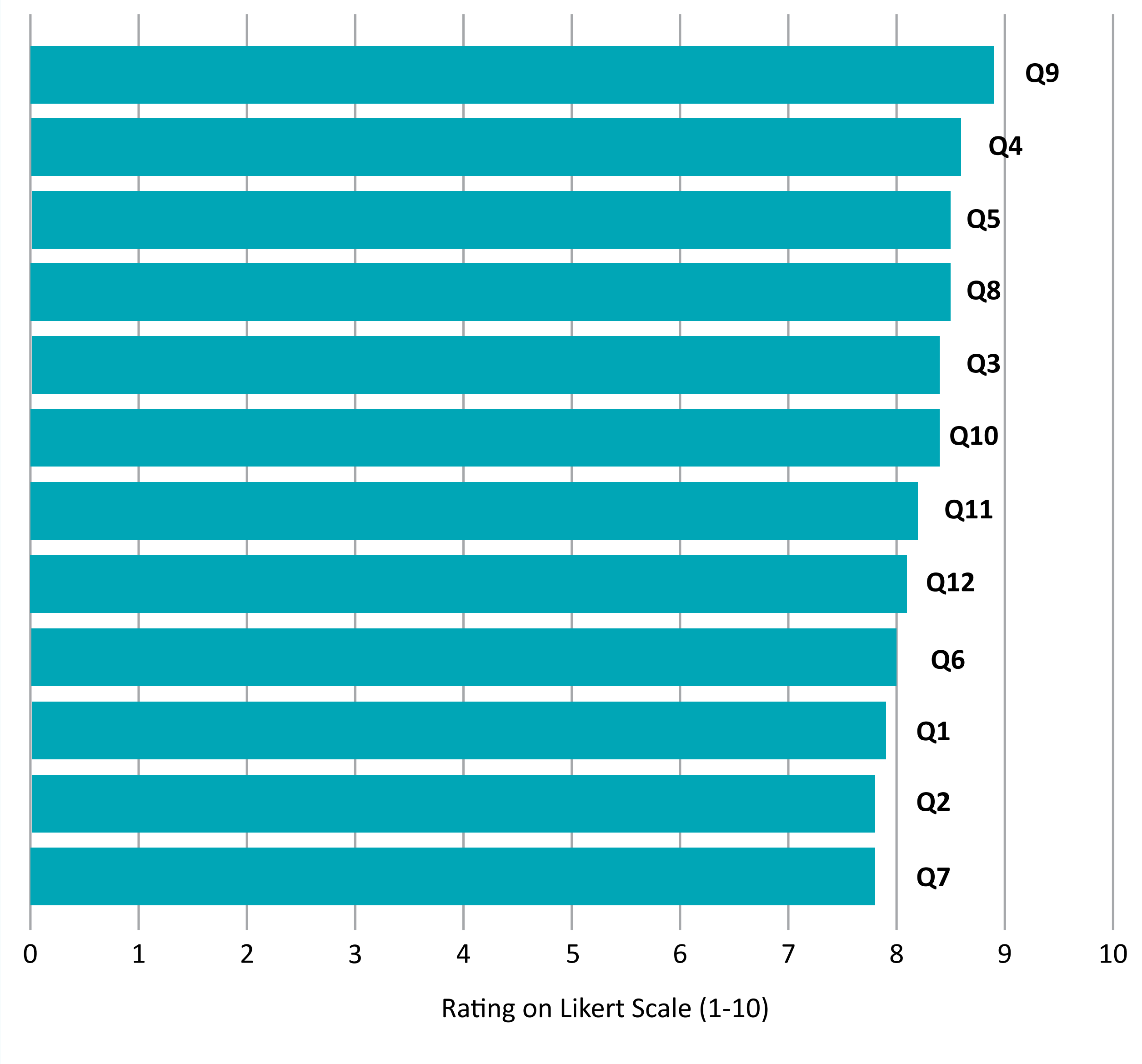
After the Knowledge Exchange Series, participants completed a survey to prioritize the most important research questions and promising solutions for each underserved population.

Top three rated research questions and promising solutions for *people living with dementia.*

	Top 3 Questions to Answer	Top 3 Solutions to Consider
1	**Practice/Care** How can we support people with loved ones that have dementia and are still living at home?	**Education/Training** Include palliative care in nursing programs and orientation sessions when employees start working in health authorities.
2	**Education/Training** Do families understand the transitions associated with different stages of dementia? Are providers explaining what to expect as the disease progresses?	**Community Engagement** Outreach with the community to promote awareness about what community services are available.
3	**System/Program Planning** How can we streamline documentation to prevent silos and support integrated, cross-disciplinary care planning?	**Practice/Care** Create a standardized operating procedure on when conversations about goals of care, disease progression, etc. should happen.

The average importance rating for each priority research question related to ***people living with dementia.***

Priority Research Questions: What do you want to know or solve? *(Session 3 Breakout 1)*		
Question		**Average Rating**
1	Research: How can we better understand and respond to the unique needs of long-term care (LTC) residents?	**7.9**
2	Practice/care: What is and what should be the role of primary care providers in supporting patients living with dementia in the community?	**7.8**
3	Education/training: How can we ensure patients and families understand what palliative care is and what it encompasses?	**8.4**
4	Education/training: Do families understand the transitions associated with different stages of dementia? Are healthcare providers explaining these stages to families, such as what to expect as the disease progresses?	**8.6**
5	System/program planning: How can we streamline documentation processes to avoid siloed records and ensure integrated care planning across disciplines?	**8.5**
6	Research: How can we improve early screening and identification of dementia to ensure individuals can access appropriate programs, supports, and interventions as early as possible in their care journey?	**8.0**
7	System/program planning: How can we restore or establish full dementia care wards in rural communities?	**7.8**
8	Practice/care: How can we increase access to respite beds?	**8.5**
9	Practice/care: How can we support people with loved ones that have dementia and are still living at home? *(Highest Rated)*	**8.9**
10	Practice/care: Where do families fit into team-based care? What are their needs and how can we facilitate a triad of care – provider, family, and patient?	**8.4**
11	System/program planning: How can we better leverage the existing depth of resources, tools, and services in BC by improving their accessibility and ensuring they reach the people who need them most?	**8.2**
12	System/program planning: How can we improve inter-team communication and collaboration—among nurses, care aides, recreation therapists, and others—to support the development of consistent, person-centred care plans? What strategies can enhance the frequency and effectiveness of this communication across teams?	**8.1**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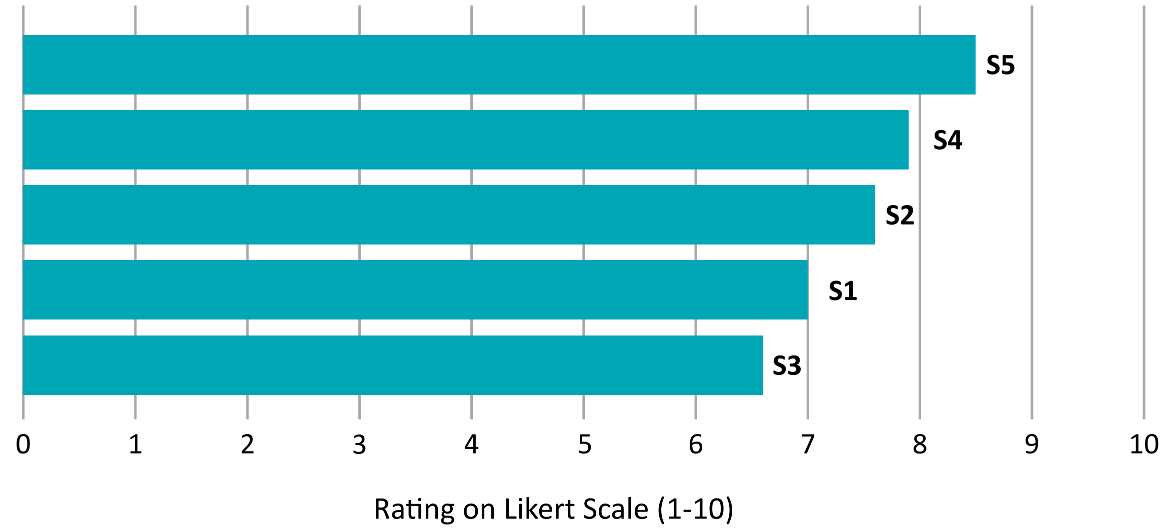
Rating on Likert Scale (1-10)

The average importance rating for each priority promising solution related to *people living with dementia.*

Priority Research Solutions: What can be done right now and by who? *(Session 3 Breakout 2)*

	Solution	Average Rating
1	Practice/care: Implement structured team reports to systematically integrate communication into existing workflows.	**7.0**
2	Practice/care: Create a standardized operating procedure on when conversations about goals of care, disease progression, etc. should happen, and how often regular updates should be provided.	**7.6**
3	Education/training: Leverage advertising or communications for resources.	**6.6**
4	Community development: Outreach with the community to teach about what community services are available.	**7.9**
5	Education/training: Include palliative care in nursing programs and orientation session when employees start working in health authorities. *(Highest Rated)*	**8.5**



For similar insights on other underserved populations, visit the BC Centre for Palliative Care website here.

BC Centre for
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Advancing palliative care through best practices, innovation and collaboration.

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