

Acknowledgements

- The Lived Experience Network
- Behavioural Support Services Leadership Team
- Alzheimer Society
- SE LHIN





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in partnership with the Alzheimer Societies of S.E. Ontario

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Lived Experience Network

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The Lived Experience Network:

1. Collaboration with the five S.E. Ontario Alzheimer Societies of lived experience persons for ongoing advisory conversations.
2. Face-to-face and telephone conversations.
3. Virtual Conversations through The Lived Experience Café at www.dementiacrossroads.ca

To Date:

178 Lived Experience Persons

48 Lived Experience Café Members

209 Live Conversations



Purpose of Network:

To facilitate the active and meaningful participation of persons with lived experience of the SE Ontario (senior) responsive behaviour population:

- in the planning, design, and implementation of BSO projects;
- education and capacity enhancement of Behavioural Support Services staff
- the evaluation process.

Listening to the Lived Experience:
A Template for Change



www.dementiacrossroads.ca

Findings:

- Based on the feedback of 200 "lived experience" advisory conversations with 173 persons living with dementia and care partners in SE Ontario, discover the **six main priorities (in no particular order)** valued by this group as critical factors to quality healthcare. This information will act as a template to meaningfully inform the support and services provided to seniors.

Priorities Valued:

- Dignity
- Consistency in the Care Journey
- Clear Communication
- Sufficient Staff and Services
- Knowledge & Skill
- Care & Compassion



Dignity

- Dignity surfaced as a priority when people felt health care providers could no longer “see” the person they were caring for as a person with history, value and importance. They felt the patient/resident/client was simply being “processed”.

Dignity


- Respecting People's Clothing & Belongings
- Transitions
- Times of Diagnoses
- Stigma
- Things are improving
- Praise



Consistency in the Care Journey

- Consistent Care for Care Partners
- Consistency in Client's Care
- Praise





Clear Communication

- Clear Communication was a priority listed by people as essential to quality care. Information sharing clearly and concisely with all parties connected to a person with dementia is difficult but needed.



Consistency in the Care Journey

- The need for consistent care as people with dementia, their families and care partners travel through the various transition points of their disease was a **top priority** named by persons within the network. Not only for the persons with dementia but also their care partners and families as they supported and helped navigate care.

Clear Communication

- Inter-professional Communication
- Knowing the Patient
- Communication within & from Services
- Texting
- Information Sharing
- Neglecting to Follow Up
- Contact the Care Partner
- Praise



Sufficient Staff & Services

- Sufficient Staffing and Services was a priority that arose in the lived experience conversations. This was an area where there were several gaps identified.



Sufficient Staff & Services

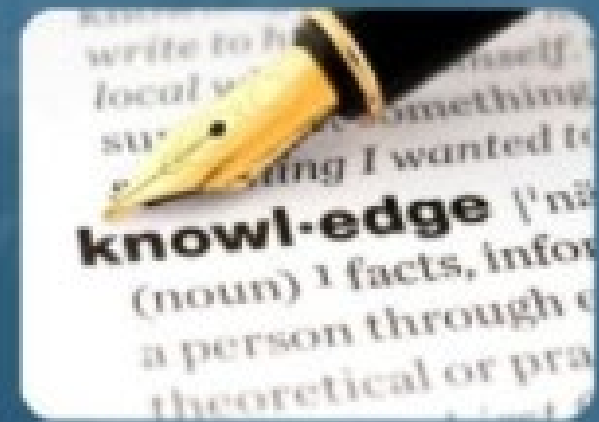
- Lack of Essential Services
- Long Waiting Lists
- Short-Term Respite Care
- Care for Both Spouses Together
- Services for people under 65
- Dental and Physiotherapy
- Transitions
- Staffing

Knowledge & Skill

- *There needs to be better education when it comes to dementia,*” was a common statement. But, when you put all the conversations together, it was more than just education they were requesting, **it was a broader base of knowledge and skill in many areas of elder care and society as a whole.**

Knowledge & Skill

- Primary Care
- Personal Support Worker Education
- Emergency Room
- The General Public
- Assessments
- Medications
- Praise





Care & Compassion

- The final theme that arose as a priority for families and care partners was the need for care and compassion to be extended to them while accepting services and supports – **without being made to feel a burden.**

Feedback?

- Did these priorities resonate with you?
- Did I miss anything?
- Do you have anything to add?
- Email your feedback to: sosvald@alzking.com

Social Media

- Facebook: Virtual Lived Experience Network Coordinator
- Twitter: [@SharonOsvald](https://twitter.com/SharonOsvald)

Every good conversation starts with good listening.

In Conclusion:

These six priorities will act as a template for how we can examine the services & supports we provide:

1. **Dignity**
2. **Consistency in the Care Journey**
3. **Clear Communication**
4. **Sufficient Staff and Services**
5. **Knowledge and Skill**
6. **Care and Compassion.**

