

Lived Experience Network

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

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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



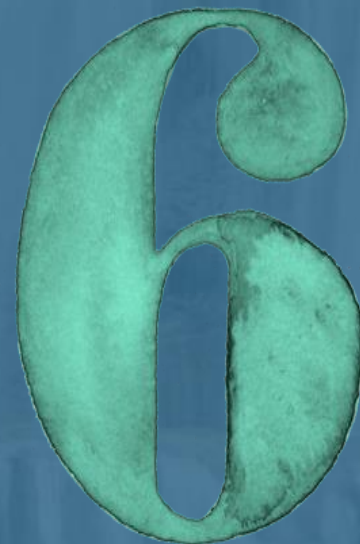
www.dementiacrossroads.ca

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

- 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.

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.

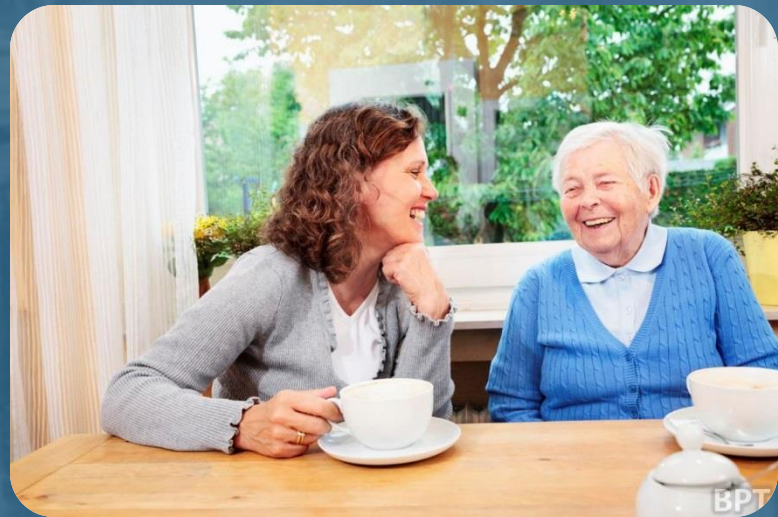
Clear Communication

- 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.**

Care & Compassion

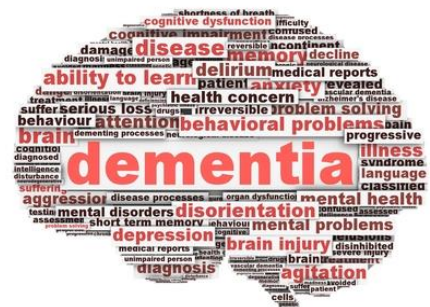
- Care Partners are Traumatized
- Feeling Resented
- Hospitals & Seniors
- Short-Term Respite Care



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.



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

**Every good
conversation
starts with
good listening.**

Acknowledgements

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



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