



HOW WE STARTED

The Lived Experience Network South East Ontario began as a project in 2013, driven by the recognition that it was not enough to simply hear the voices of those with lived experience. We wanted to ensure the lived experience perspective was embedded in everything we do.

Initially these conversations took place in person, but quickly moved to a live chat forum, then to Zoom. Conversations are hosted by the Lived Experience Facilitator, a funded position since 2016 through a partnership with the Kingston, Frontenac, Lennox & Addington Alzheimer Society and Providence Care.

LIVED EXPERIENCE NETWORK THREE PILLARS

Pillar 1 – Growing the Lived Experience Network
~Recruiting and maintaining membership

Pillar 2 – Awareness and Knowledge Exchange
~Sharing information about and produced by the network

Pillar 3 – Lived Experience Voice in the System
~Consultations and live chats

~Exchanging Knowledge, Partnering for Change~

WHO ARE THE LIVED EXPERIENCE ADVISORS?

- People living with dementia
- Family care partners of people living with dementia
- Individuals with experience navigating health and community care systems across Southeast Ontario

We currently have:

31 active participants (including 2 since 2013)

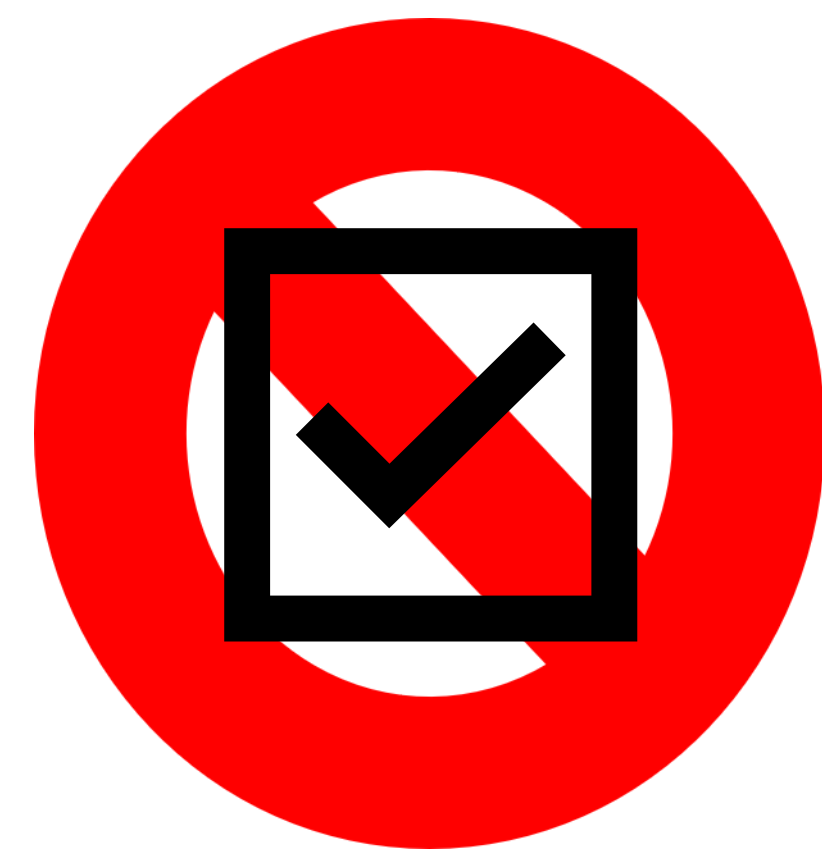
157 passive participants

160 professionals receiving chat summaries

5000 website visits per year

KEY ELEMENTS TO SUCCESS

- Sustained co-design and shared leadership
- Engagement of lived experience advisors as equal partners in health system design and delivery, with clear feedback on how their input has informed decisions and contributed to meaningful system change.
- Lived experience advisor input is anonymous
- System actively seeking and open to lived experience feedback
- Stable and secure funding for the Lived Experience Facilitator position



Lived Experience is More Than Just a Checkbox: Meaningful Inclusion of Lived Experience Perspectives in Seniors Mental Health System Planning



LIVE CHATS – ENGAGING THE VOICE OF LIVED EXPERIENCE ADVISORS

System asks a question

Lived Experience Facilitator creates chat topic

Lived Experience Network chat to solicit input

Lived Experience Facilitator creates chat summary

Chat Summary sent to group asking the question

Chat summary posted on Lived Experience Network Website

Lived Experience Chats are designed to provide valuable insights based on individuals' experiences throughout the dementia journey, helping to inform and shape programs, services and decision making.

Examples of chat topics:

~ From our funders: What was or what do you anticipate to be your breaking point in the community?

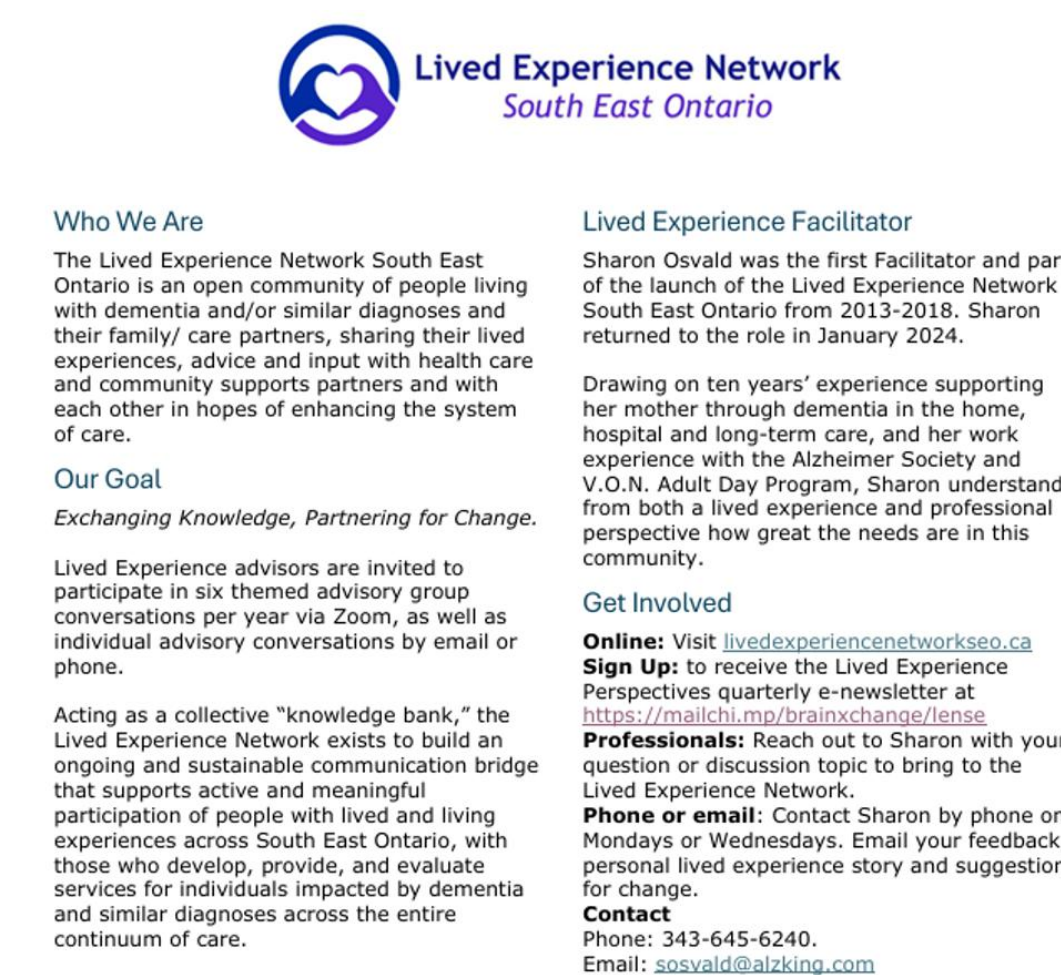
~From a Family Health Team: How do we approach the topic of Long-Term Care with our patients?

~From the local Alzheimer Societies: What barriers do you face in participating in programs, activities and education?

~ From Providence Care: We are looking for input to refine and improve our central access service. Come prepared to share your lived experiences accessing services throughout your dementia journey.

I am seeing improvement. What I saw when we were first trying to get a referral [pre Central Intake], to what I see and hear now, amazing changes and improvement has occurred, and I think that should be applauded and recognized. It also means we can continue to look at strategies to continue to grow and improve.

Lived Experience Advisor
Feedback on Central Access Service
October 2025



The Lived Experience Network South East Ontario information sheet

NEXT STEPS

- **Continue to build a sustainable and inclusive community of advisors** that supports meaningful participation of people with lived and living experience, including opportunities for local leadership.
- **Enhance the use of social media and digital communications** to promote the network, share key findings, encourage participation, and increase awareness of advisory conversation opportunities.
- **Increase awareness of the network as a valuable source of lived experience expertise** for health care providers, planners, researchers, and decision-makers seeking to improve programs, services, and system design.

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