Sharon Osvald

Kathy Baker and Kim Schryburt-Brown

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

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

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?

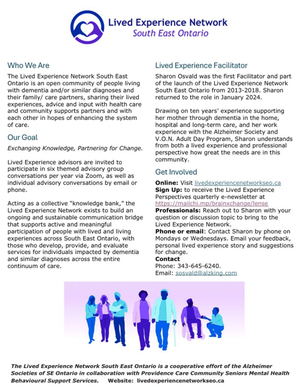
~From a Family Health Team: How do we approach the topic of Long-Term Care with our patients?

~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



Lived Experience Network
South East Ontario

Who We Are

The Lived Experience Network South East Ontario is an open community of people living with dementia and/or similar diagnoses and their family/ care partners, sharing their lived experiences, advice and input with health care and community supports partners and with each other in hopes of enhancing the system of care.

Our Goal

Exchanging Knowledge, Partnering for Change.

Lived Experience advisors are invited to participate in six themed advisory group conversations per year via Zoom, as well as individual advisory conversations by email or phone.

Acting as a collective "knowledge bank," the Lived Experience Network exists to build an ongoing and sustainable communication bridge that supports active and meaningful participation of people with lived and living experiences across South East Ontario, with those who develop, provide, and evaluate services for individuals impacted by dementia and similar diagnoses across the entire continuum of care.

Lived Experience Facilitator

Sharon Osvald was the first Facilitator and part of the launch of the Lived Experience Network South East Ontario from 2013-2018. Sharon returned to the role in January 2024.

Drawing on ten years' experience supporting her mother through dementia in the home, hospital and long-term care, and her work experience with the Alzheimer Society and V.O.N. Adult Day Program, Sharon understands from both a lived experience and professional perspective how great the needs are in this community.

Get Involved

Online: Visit livedexperiencenetworkseo.ca
Sign Up: to receive the Lived Experience Perspectives quarterly e-newsletter at: livedexperiencenetworkseo.ca/newsletter
Professionals: Reach out to Sharon with your question or discussion topic to bring to the Lived Experience Network.
Phone or email: Contact Sharon by phone on Mondays or Wednesdays. Email your feedback, personal lived experience story and suggestions for change.
Contact
Phone: 343-645-6240.
Email: sosvald@alzking.com

The Lived Experience Network South East Ontario is a cooperative effort of the Alzheimer Societies of SE Ontario in collaboration with Providence Care Community Seniors Mental Health Behavioural Support Services. **Website: livedexperiencenetworkseo.ca**

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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Lived Experience Network South East Ontario Newsletter