

Caregivers As Partners Knowledge Mobilization Day

Summary Report: Advancing Caregiver
Inclusion Across Ontario's Health System



“Our healthcare system focuses on the patient, but too often overlooks the person standing right beside them. When caregivers are ignored, the burden doesn’t just shift—it multiplies. Caregivers are the quiet backbone of care, but even a backbone has limits. If we want a resilient healthcare system, we must begin by caring for the people who hold it together.”

— Dave Rundle, Caregiver



Caregivers play a critical role in care delivery: impacting quality, health outcomes, and safety for patients and healthcare providers alike.

In Ontario alone, 4.2 million people are caregivers. This number is expected to grow to 6.5 million by 2030. Despite this, many feel invisible. According to [data from the Ontario Caregiver Organization](#), 68% are reaching their breaking point. This growing pressure is touching everyone, from patients to care teams across all sectors.

The challenge is clear. We see its scope. But what can we do?

On February 26, 2026, the Ontario Caregiver Organization's Essential Care Partner Support Hub in collaboration with Trillium Health Partners' Institute for Better Health brought together more than 120 caregivers, patients, healthcare providers, researchers and system leaders from across Ontario for a focused, collaborative forum to advance caregiver-inclusive care.

Caregivers as Partners Knowledge Mobilization Day showcased leading practices already underway across Ontario, elevated caregiver voices, surfaced persistent system barriers, and accelerated action toward more consistent caregiver inclusion. It also created space for cross-sector dialogue and collaboration, with a focus on translating shared learning into tangible next steps for organizations and system partners.

This report summarizes the key discussions, lived experiences, and emerging insights from the day, and highlights practical approaches and system opportunities to better identify, include, and support caregivers across the continuum of care. (See the At-A-Glance itinerary on [page 7](#).)

Caregiver voices set the tone throughout the day.

Sharing their lived experience navigating hospitals, home care, and transitions across settings, their message was clear: caregivers are essential. Across the system, it's their partnership that holds care together.

A photovoice exhibit powerfully portrayed the lived experience of women caregivers who documented and shared how they have been balancing care across generations. Combining photographs and personal narratives, the exhibit brought critical visibility to their multiple, intersecting caregiving roles while generating momentum for further research and action.



“Caregivers have knowledge and experience no one else does.”

- A Participant from
Caregivers as Partners
Knowledge Mobilization Day



Across sectors, organizations demonstrated real progress.

From early caregiver identification and EMR flags to embedding caregivers in care planning, discharge processes, and structured education and support pathways, teams showed us that real change is already underway.

We investigated barriers and solutions.

The need to strengthen integrated care across organizations is urgent. These “spaces in between” are delicate: it’s often where care becomes the most fragmented, and where caregivers get the least support.

By opening up about their challenges, participants made space to learn what could solve them: from improving cross-sector communication to standardizing caregiver-inclusive practices and scaling caregiver support and coordinated care models.

“Acknowledging a caregiver and what they’re experiencing goes so far.”

- Brina Ludwig-Prout, Essential Care Partner Advisory Committee Co-Chair



“It’s about learning, unlearning, growing, and having impact together-across clinicians, teams, organizations, sectors, communities and in equal partnership with people with lived and living experience (patients, clients), caregivers and communities themselves.”

- Jodeme Goldhar, Vice Chair, International Foundation for Integrated Care Board, Founder and Managing Director, 4C IMPACT, Co-Director NACIC University of Toronto, Co-Director, National Health Fellows Program Health Leadership Academy McMaster University



What we learned, and what we can do

We have a lot of work to do to truly include and support caregivers as essential partners, but there's an incredible amount of progress being made. To drive system-wide change across Ontario, we must be intentional; taking stock of all the different touchpoints caregivers and patients navigate across the continuum of care.

We learned a lot from the expertise of care teams, researchers, organizational leaders and caregivers at our Knowledge Mobilization Day.

Here's what they shared, and how you can start.



It takes leadership. When leaders prioritize caregiver inclusion, it gives teams a clear direction with which to align their work, making change sustainable.

- Senior leaders can champion caregiver inclusion by embedding it into strategy, policy, and resource allocation. OCO's [Learning Collaborative](#) creates a space for leaders and providers to hear how other organizations are doing the work.



Caregivers are the indispensable heart of integrated care. Their inclusion strengthens safety, care continuity, and overall organizational effectiveness; improving transitions, cross-sector collaboration, and benefiting care recipients, caregivers, and staff alike.

- Understand and engage caregivers to learn from their lived experience and bring the expertise they offer to partners, colleagues, and leadership. OCO can help by providing practical [co-design guidance](#) and [storytelling tools](#) to support meaningful caregiver engagement in your setting.



Supporting caregivers is critical. Caregivers are struggling. Early identification and connection to resources can address burnout and improve outcomes for both caregivers and care recipients.

- Set up processes for staff to easily identify caregivers and connect them to support. OCO can provide your setting with free caregiver [postcards](#), and [toolkits](#) that connect caregivers to the [Helpline](#).



Education enables action. Training and practical tools help to equip all staff with the skills to identify, include, and support caregivers.

- Build capability and sustain culture change by educating staff about the critical role of caregivers and the importance of early identification. OCO offers [education opportunities](#) and [practical resources](#) to make it easy.



Infrastructure changes culture. Integrating caregivers into documentation, EMR workflows, and care pathways enables a culture of caregiver inclusion and support by reducing communication gaps

- Develop and co-design care pathways with caregivers to enable formal identification, inclusion and support. OCO offers multiple resources including [caregiver ID templates](#) and [infographics](#) to help embed the involvement of caregivers across all care settings.

Looking ahead

The message is clear (and urgent): caregiver inclusion isn't optional, it's essential to building a sustainable, high-performing health system.

Across Ontario, the momentum is growing.

Organizations are already demonstrating that meaningful change is possible when caregivers are recognized, identified early, and supported as partners in care. However, system-wide impact entails moving beyond isolated efforts toward consistent, coordinated approaches embedded in everyday practice.

Ontario has a significant opportunity to embed caregiver-inclusive care as a standard across all sectors, with:

- Committed leadership,
- Strong cross-sector collaboration,
- Robust education, and
- Scalable practical resources and tools.

Sustaining this momentum will depend on continued partnership with caregivers, ensuring their voices remain at the centre of system design and improvement.

Because when caregivers are supported, patients receive better care, providers are better equipped, and the health system as a whole becomes more resilient.

Feeling inspired?

Get free hands-on, 1:1 support to help you advance caregiver inclusion at your setting — whether you don't know where to start, have an idea, or want to grow current programs, policies, and initiatives.

OCO's [Essential Care Partner Support Hub](#) has worked with hundreds of healthcare organizations across Ontario to build solutions that support caregivers and align with their organization's goals, without adding burden on staff.

[Connect with us today](#)



100%

of participants reported the Knowledge Mobilization Day was highly valuable and energizing

Knowledge Mobilization Day at-a-glance

Key voices

- Amy Coupal, CEO, Ontario Caregiver Organization
- Video remarks from The Honourable Sylvia Jones, Deputy Premier and Minister of Health
- Judy Linton, Acute and Hospital-Based Care Executive Vice-President, Chief Nursing Executive, Ontario Health
- Dave Rundle, Caregiver
- Jodeme Goldhar, Vice Chair, International Foundation for Integrated Care Board, Founder and Managing Director, 4C IMPACT

Adoption in Action: How healthcare organizations across health settings are identifying, including and supporting caregivers

- *Moderator: Brina Ludwig-Prout, Essential Care Partner Advisory Committee Co-Chair*
- Couchiching Family Health Team & Couchiching Ontario Health Team
- Lakeridge Health & Lakeridge Gardens
- Northumberland Hills Hospital & Ontario Health Team Northumberland

Insights from the Support Hub - What We've Learned & What You Can Do

- Alison Kilbourn, Manager, Essential Care Partner Support Hub, Ontario Caregiver Organization

The view from here: Perspectives on caregiver identification, inclusion and support across & in between the health system

- *Moderator: Dr. Kerry Kuluski, Professor, Affiliated Scientist, Institute for Better Health, Trillium Health Partners and University of Toronto*
- Jennifer Cornell, Grey County
- Dr. Laura Istanboulia, Michael Garron Hospital
- Trevor Heer, VHA Home HealthCare & Champlain Rehab Solutions
- Elisabeth Catalano-Bon, Peel Region
- Dr. Jason Kerr, Trillium Health Partners
- Francine Buchanan, Caregiver, Researcher
- Bhavini Patel, Caregiver