



THE ONTARIO

caregiver

ORGANIZATION

Integrating Caregivers as Partners in Care:

Momentum for a Whole-System Approach

Report from
the 2024



Caregivers as Partners in Care Roundtable



ABOUT THE ONTARIO CAREGIVER ORGANIZATION

Our Purpose: The Ontario Caregiver Organization (OCO) exists to improve the lives of Ontario caregivers: ordinary people who provide physical and emotional support to a family member, partner, friend, or neighbour.

The OCO offers a range of direct supports and services for caregivers. We work with system partners, organizations, caregivers, and government to address gaps and generate solutions that improve caregiver experiences and patient outcomes.

In early 2023, the OCO launched the [Essential Care Partner Support Hub](#) in partnership with Ontario Health. This initiative aims to achieve greater consistency in how family caregivers are identified, included, and supported as essential care partners across care settings in Ontario.

SPECIAL THANKS AND ACKNOWLEDGEMENTS

We would like to thank everyone who participated in the Roundtable, including our speakers, panelists, moderators, table facilitators, and all participants, with special thanks to the caregivers and patients who contributed their knowledge and time.

Extra special thanks to caregiver Terrence Ho for sharing his personal insights and lived experience as a keynote speaker, setting the stage for a day of meaningful discussion and lasting impact.

Thank you to the Roundtable Planning Committee that played a key role to guide and inform event planning: Brina Ludwig-Prout, Lester Krames, Carla Velastegui, Andrea Rovazzi, Jennifer Cornell, Michelle Fleming, Jennifer Ridgway, Carol Fancott, and Paula Doering.

We would like to acknowledge Christa Haanstra for her key role in preparing this report. Many thanks to the ClarityHub team (Christa Haanstra, Alison Steeves, Elizabeth Dempsey, and Michelle Wan) who were instrumental in planning and delivery of the Roundtable resulting in a successful day of learning, reflection and engagement for all involved.



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HIGHLIGHTS FROM THE 2024 CAREGIVERS AS PARTNERS IN CARE ROUNDTABLE

Key Themes: Realities, Needs & Challenges:



Caregivers must be central to health care transformation



System barriers add to caregiver load



Rising caregiver stress and complexity of caregiving



Lack of access to primary care affects caregivers



Caregivers play a key role in equitable care



Home and community care has an integral role to play

Promising Signals & Opportunities for Change:



Recognition of the importance of caregivers is growing



Health system transformation = opportunities for caregiver integration



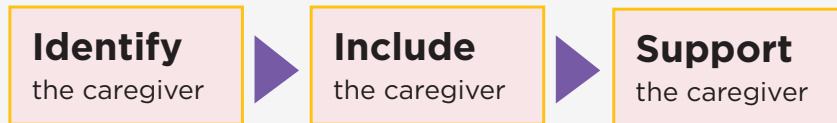
Models of excellence in caregiver integration are ready for spread and scale



OCO's Essential Care Partner Support Hub is accelerating the adoption of caregiver-inclusive practices

The journey to a more connected, inclusive, and caregiver-integrated health care system is not just aspirational - it's achievable.

From Insights to Action:



Three simple things that have the potential to transform our health care system and life for many Ontarians.

Now is the time to come together and make lasting change that recognizes the role of caregivers.

- ✓ Demonstrate leadership and commit to caregivers as a priority
- ✓ Embrace a culture that includes caregivers as partners in care
- ✓ Invite caregivers to share their experience and expertise
- ✓ Identify and break down silos – a whole-system approach is needed
- ✓ Facilitate information sharing and integrate digital health systems
- ✓ Apply the caregiver lens on plans for health care transformation
- ✓ Expand accessibility and availability of caregiver supports
- ✓ Include caregivers – every time



System-level



Organization-level



Point of care



We have a collective responsibility to foster a health care system that integrates caregivers as essential to compassionate, informed, equitable, safe, and effective care.

INTRODUCTION

In early 2024, the Ontario Caregiver Organization (OCO) convened over 90 people from across Ontario for the Caregivers as Partners Roundtable to envision a future where caregivers are consistently valued, recognized, and supported across the whole health system.

The event drew a broad range of perspectives including caregivers, patients, system leaders, government, academics, and point-of-care providers, enabling rich cross-sector dialogue.

The Roundtable was more than just a meeting; it was a pivotal event for OCO and caregivers in Ontario. Coinciding with the one-year anniversary of the launch of the [Essential Care Partner Support Hub](#), it represented a critical step forward in advancing the adoption of caregiver-inclusive practices into the culture of health care in our province.

ROUNDTABLE GOAL:

To build on the progress of integrating caregivers as essential care partners across all health care settings in Ontario and collaborate on future opportunities to advance the recognition and empowerment of caregivers.

The Roundtable brought to light many of the challenges faced by caregivers, patients, and providers. We heard about the silos and challenges that need to be addressed for caregivers to be recognized and empowered as true partners on the care team.

We also saw examples of excellence in caregiver inclusion and emerging opportunities to include caregivers as a key part of Ontario's shift to more people-centred, integrated care.

The message was clear:

- The time is now. The lived experiences of patients, residents, clients, and caregivers need to be central to the future of health care.
- Identifying, including, and supporting caregivers as essential care partners is critical and doable. There are collective steps we can take to make a difference immediately, and longer-term changes that will have a lasting impact on health care in Ontario.

As one of our Roundtable delegates said, “keep essential care partners, and the need for integration, at the forefront of all aspects of health care.”

This report highlights key insights and themes from the Roundtable event and outlines a clear call to action to create a future where caregivers are integral to the fabric of health care in Ontario.

ROUNDTABLE – AGENDA HIGHLIGHTS

Event host and emcee: Amy Coupal, CEO, Ontario Caregiver Organization Special Remarks: The Honourable Sylvia Jones, Deputy Premier and Minister of Health Keynote: Judy Linton, Ontario Health Caregiver Keynote: Terrence Ho	
Integrating Caregivers as Team Members Moderator: Paula Doering, Bruyère	<ul style="list-style-type: none"> Deborah Simon, Ontario Community Support Association John Yip, SE Health Jennifer Cornell, County of Grey Long-Term Care
Reflections from the Front Lines of Care Moderator: Brina Ludwig-Prout, Caregiver	<ul style="list-style-type: none"> Dr. Tara Kiran Dr. Nathan Stall Dr. Dominik Nowak Chantelle Mensink, NP
Whole system approach to integrating caregivers as essential partners: A view from Ontario Health Teams Moderator: Susan Palijan, Caregiver	Algoma OHT <ul style="list-style-type: none"> Victoria Aceti-Chlebus Laura Tenhagen Louis Ferron, Caregiver East Toronto Health Partners <ul style="list-style-type: none"> Nena Pendevska Hannah Trumper, Caregiver



POST-EVENT SURVEY:

100%

said the Roundtable helped identify practical ways that we can build a “whole-system” approach to including and supporting caregivers



Over 90 participants: 20 caregiver and patient participants + system and organizational leaders, government and health policy, academics, and point-of-care providers.



Participants shared professional and lived experience across home and community care, primary care, hospitals, long-term care, and the connections between care settings.



Caregivers engaged in all aspects of the Roundtable as committee members, speakers, panel and table facilitators, and participants.

Roundtable discussions set the stage for rich conversations, exploring questions like:

- How can identifying, including, and supporting caregivers help to break down the silos of care?
- What is currently standing in the way?

“I felt heard as a caregiver by people who can make change”

– Caregiver delegate

KEY THEMES: REALITIES, NEEDS, AND CHALLENGES

The presentations, panels, and roundtable discussions outlined a clear call for change and highlighted the need to work together to improve the system. We all want a health care system where working with caregivers is not just important but a key part of more integrated, people-centred care.

Caregivers must be central to transforming health care

It's not a well-known fact: 75% of care is provided by family caregivers. But in his keynote speech, caregiver Terrence Ho shone a spotlight on this reality when he showed a weekly calendar for the care schedule for his brother, and highlighted all the hours when the family held primary caring responsibility.

With this understanding, how can we lead change in the health care system without the inclusion of caregivers? It is not just beneficial to have caregivers included in conversations about health care transformation - it's absolutely vital.



	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
9:30 - 11:30 AM	PSW	PSW	PSW	PSW	PSW	PSW	PSW
11:30 - 12:30	Family	Family	PSW	Family	Family	Family	Family
12:30 - 3:30 PM	PSW	PSW	PSW	PSW	PSW	PSW	PSW*
3:30 - 4:30 PM	Family	Family	Family	Family	Family	Family	Family
4:30 - 6:30 PM	Family	Family	Family	Family	Family	Family	PSW
7:00 - 9:00 PM	Family	PSW	Family	PSW	PSW	Family	PSW
9:00 - 9:30 PM	Family	Family	Family	Family	Family	Family	Family
9:30 - 11:30 PM	Family	Family	Family	Family	Family	Family	Family
11:30 - 9:30 AM 10 hr Overnight Shift	Family						

*Exception is Sunday when it is 12:30 to 2:30 PM

System barriers add to caregiver load

Our panelists shared their experiences and realities, including systemic obstacles, that they face in their daily lives as frontline providers, system leaders and family caregivers. These challenges make it hard for health care professionals and caregivers to work well together and also add to the stress caregivers face.

- **Siloed system:** The siloed structure of our health care system poses a barrier to delivering integrated care. The disconnect between different parts of the system means caregivers are navigators by default. Caregivers are the common link between all the disparate parts, which is an enormous responsibility for which they often have no training or support.
- **Data and digital system challenges:** A significant barrier highlighted was the lack of integration across digital health care platforms, complicating the exchange of vital patient information. Most of our health data systems do not have a place to identify and document caregivers, making it challenging to integrate them as partners in care and collect data about their needs and experiences. Caregivers feel the deep burden of digital systems that don't connect.
- **Limitations of current funding models:** Renumeration policies and funding agreements are focused on the patient and generally don't include compensation for the time and benefit of engaging and supporting caregivers. In cases where caregiver support is provided, the benefits are clear.
- **Time and resource constraints:** With the health human resource shortage and increasing demands on the health care system, the time that each health care provider has with patients is limited. This leaves even less time to acknowledge caregivers and their needs, or involve them in discussions about treatment plans or discharge

"We need to come out of our silos, and see what it is the system was designed to do - support patients and caregivers to get the help they need."

- Dr. Tara Kiran

"Families don't see the silos and are key ingredients to identify and break down the silos. They question the silos and ask the important questions."

- Caregiver delegate

"Caregivers are the ones who share information between care providers, specialists -how do we make this easier?"

- Roundtable delegate

"Everything we do for the patient is also to support the caregiver. The referral to day program, home care hours, resources, and supports. If the caregiver is supported, the person can stay at home longer."

- Chantelle Mensink, Nurse Practitioner, New Vision Family Health Team

"We've built organizations to do everything by themselves, not to collaborate. The funding structures we have in place enable that, and we need to change those funding structures in order to change organizational culture."

- Roundtable delegate

planning. Service gaps and long wait lists are also a concern. Caregivers are left scrambling to pick up the pieces without support, which often leads to readmissions, more appointments, and poorer health outcomes for patients.

Rising caregiver stress and complexity of caregiving roles

Dr. Nathan Stall captured the essence of a looming crisis with a clarity that demands attention: the future of caregiving, reflected by hard data and demographic trends, is no longer a distant concern but an imminent reality.

In Ontario today, there are 600,000 people living with dementia. By 2030, the number will increase to 1 million. “Dementia is known to be one of the most caregiving-intensive diseases.”

“We’ve already seen a doubling in caregiver stress, for those caring for people with dementia, between 2010 and 2021,” explains Dr. Nathan Stall. System factors that are contributing to added stress are:

- Increasing strain on the home care system
- Increasing complexity of people still living at home
- Lack of supports and resources for caregiving

This only considers the segment of caregivers who are caring for people living with dementia. Those supporting a person with other physical or mental health needs are also feeling the strain. OCO’s latest Spotlight Report indicated that 67% of caregivers say they hit their breaking point but know they have no choice but to keep going. The future of caregivers is at risk if we don’t start making change now.

Lack of access to primary care affects caregivers

2.3 million Ontarians do not have access to a primary care physician. Couple that with the administrative burden on primary care (19 hours/week for each primary care practitioner), and it’s clear that a system-wide solution is needed. Without primary care, described as the ‘front door of care’, family caregivers bear the brunt of this lack of access.



“Surround everyone with a primary care team. And that team includes the family caregiver,” explained Dr. Dominik Nowak. “The trifecta – the family doctor, the patient, and their caregivers – is important as we look to a sustainable approach to health care into the future.”

“How can we re-orient the health care system so it is in service to the people it is meant to serve?”

– Dr. Tara Kiran

Dr. Tara Kiran spoke about the [OurCare Standard](#) for the future of primary care that is based on recommendations from thousands of Canadians who shared their perspectives and experiences. “Everyone agreed that primary care needs to be inclusive, comprehensive, and accessible to all”.

Caregivers play a key role in equitable care

Roundtable delegates identified the need for more focus on the social determinants of health and how they impact the caregiving experience. Caregivers are often critical to ensuring culturally-sensitive care for racialized, 2SLGBTQ+, and Indigenous patients. Language, income level, cultural background, race, and gender and sexual identity are factors that can impact the caregiver role and access to services for both the patient and caregiver.

“When caregivers are included, the system benefits, especially at transition points where they provide information not just about health issues but about who the care recipient is, what they need in terms of culturally affirming and linguistically appropriate care. This allows providers to provide better care.”

– Sam Peck, Executive Director, Family Councils of Ontario

Home and Community Care: Supporting Caregivers and Strengthening Communities

Roundtable discussions made it clear that a whole-system approach to caregiver inclusion cannot happen without home and community care as an integral and central part of the discussion.

Deborah Simon, CEO of the Ontario Community Support Association, drew attention to the importance of community support services as a foundational part of support for caregivers that is often overlooked. “These services have been around for decades... providing trailblazing services to support caregivers well before people started to think that caregiver support was really important.” Community support service programs like Meals on Wheels, friendly visiting, and transportation services are more than just assistance—they are vital lifelines that allow patients to live and thrive in their own communities and play a crucial role in supporting caregivers and preventing burnout.

Consistent, frequent and formal caregiver screening and assessment at “every single home care visit” was also identified as an opportunity to better understand how the caregiver is doing, recognize how integral they are to care, and connect them with the support they need.



“Partners in Care. That’s the goal.... here is that trifecta of the family member, the provider, the individual receiving the care. It does happen. Now the challenge is to make it happen every single time”

– John Yip, President and CEO, SE Health

PROMISING SIGNALS AND OPPORTUNITIES FOR CHANGE

While there are challenges to be addressed that impact the caregiver experience in Ontario today, there are many signs that the tide is changing. Now is the time for whole-system, province-wide commitment and action.

Recognition of the importance of caregivers is higher than ever before

While evidence in support of caregiver inclusion was growing before the pandemic, Covid-19 restrictions resulted in lessons about the risks and harm to patients, residents, and the health care system when caregivers are not able to participate in care.

The Roundtable event and the enthusiastic response from delegates and speakers was in itself a signal of the growing recognition that caregivers are essential.

There is also more support available for caregivers today than just five years ago. The formation of the Ontario Caregiver Organization has led to new programs and services, including the [Ontario Caregiver Helpline](#).

Health system transformation is creating opportunities for caregiver integration

There are major changes underway in Ontario's health care system. Panelists and participants spoke about Ontario Health Teams and interprofessional primary care teams as key pathways to more integrated care. These shifts represent an opportunity to break down siloes, lighten the load on caregivers, and make it easier for caregivers to be partners in care.

Caregivers have unique expertise to inform what integrated care really means. They can help to enable health care change at a system level and at point of care - but only if they have the opportunity to participate.

"How can we learn from what caregivers are doing and implement some of this into the system?"

- Roundtable participant

What important information does the caregiver have that will actually make our job easier to provide care? And that's our responsibility...To create an environment that makes it easier for the caregiver to bring that information and to be part of the team... as opposed to them carrying the burden of needing to interject and say hey, 'I have something to say - I have information but you're not listening'. We need to make that space and include them as part of the care team.

- Jennifer Cornell, Director of Long-Term Care, County of Grey

“Whole system care starts with the whole person. We’re in this together. Let’s solve it together.”

– Terrence Ho, caregiver keynote speaker



Showcasing Excellence and Models for Spread and Scale

The Roundtable highlighted examples from across the province where organizations have made caregivers a priority and are seeing the benefits. Presentations from the Algoma Ontario Health Team, East Toronto Health Partners, and New Vision Family Health Team included practical approaches and emphasized the value of integrating caregivers into health care teams.

The OCO’s [Essential Care Partner Support Hub](#) is playing a key role in accelerating the adoption of programs and practices that identify, include, and support caregivers. Organizations and caregivers connected with the Support Hub receive guidance and resources, and also share their knowledge about practical ways to engage caregivers as partners in care.

There are also pockets of excellence where caregivers are actively influencing change and decisions in governance, program development, research, and at point-of-care.

We can learn from these examples and there are opportunities to spread and scale successful models across the province. It’s time to work collaboratively to increase caregiver integration.

“One thing we do at our family health team is we include our caregivers right from the beginning - about what their concerns are, what their thoughts are, how are they coping. We really work to not only meet the needs of the patient, but meet the needs of the caregiver.”

– Chantelle Mensink, Nurse Practitioner, New Vision Family Health Team



FROM INSIGHTS TO ACTION

We have a collective responsibility to foster a health care system where caregivers are integral contributors, essential to the provision of compassionate, informed, equitable, safe, and effective care.

So where do we start?

Let's start off with some simple things that we can all do to make a big difference right way within the system and organizations, and at point-of-care.

- **Demonstrate leadership:** A commitment to caregivers as a priority is a key first step. Start the conversation to build allies within your organization and across the system. Initiate and amplify efforts to implement caregiver-inclusive practices.
- **Acknowledge and validate caregivers:** By verbally recognizing family caregivers in every interaction, it validates them and recognizes their vital contributions. A simple acknowledgement is a great starting point for improved relationships and experiences for patients, caregivers, and providers.
- **Listen to understand:** Listening to understand goes beyond merely hearing words; it involves active engagement, asking insightful questions, and providing space for each voice to be heard. At point-of-care, this can lead to deeper insights into experiences, concerns, and preferences. This commitment to listening is also important for program development, at system and government level, and for research and academic projects.
- **Invite caregivers to share experiences:** Starting Board, staff, or project meetings with a presentation from a caregiver is a simple way to ground strategic discussions in lived experience. Be mindful that the caregiver experience is different and distinct from the patient's and each caregiving experience is unique.

"Don't hesitate to involve caregivers - pick things up as you go and don't be shy to ask others for help."

– Roundtable delegate



- **Seek opportunities to learn:** A major challenge in advancing caregiver support is the inconsistent recognition and understanding by both health care leaders and providers of caregivers' crucial role as team members. We can learn from those who are doing it well including pediatric care and community support services. The Ontario Caregiver Organization offers online education opportunities for providers. The Essential Care Partner Support Hub provides guidance, learning, and resources to organizations interested in implementing an essential care partner program.
- **Commit to long-term change:** Start with immediate, achievable actions, and maintain a steadfast commitment to pursuing broader, more profound shifts in how caregivers are integrated into the health care ecosystem over time.



What is needed for long-term changes across the whole system?

What are the long-term organization and system-level, more intensive changes that are needed to deepen the integration and recognition of caregivers within the health care system?

We heard repeatedly at the Roundtable that “what’s good for the caregiver is good for the patient”. A cultural shift and tangible changes in the way our health system works is needed so that patients, caregivers, and providers can work together as partners in care.

- **Embrace a Cultural and Philosophical Shift:** Solidify the role of caregivers as integral team members at point of care and treating them as vital contributors to health care system changes. This shift requires a fundamental re-evaluation of how caregivers are perceived and included, and leadership commitment for the long-term.

“A foundational enabling factor was patient and family caregiver involvement. Not only guiding what the project would look like but also holding us accountable over time to our commitment to supporting caregivers.”

– Laura Tenhagen,
Project Management
Consultant, Sault Area
Hospital



- Forge True Partnerships with Caregivers:** Establish engagement with patients and caregivers as a standard practice. Involve them directly in discussions and decision-making processes, recognizing their expertise and lived experience.
- Identify, Include and Support Caregivers:** This is the foundation of the Essential Care Partner initiative. The implementation of programs, policies and practices to identify, include, and support caregivers is a key enabler of real change. The evidence is clear. The approaches and success of organizations that have already implemented should be spread across all parts of the health care system.
- Include caregivers - every time:** The inclusion of caregivers as part of the care team is happening in some places, but there is little consistency across sectors, organizations, geography, and even within the same setting. We need to learn from those who are doing it well and change our system so that caregivers are valued as essential team members at every touchpoint.
- Identify and Break Down Silos:** When patients and their caregivers navigate the health care landscape, they don't see separate entities; they see one continuum of care. Caregivers have expertise that is needed to inform the path to more integrated care. We need to break down silos to make it easier for them to participate as partners in care without carrying the load of being the ones to bridge the gaps between various providers and services.
- Apply the caregiver lens on plans for health care transformation:** Major changes are unfolding in Ontario's health care system, including Ontario Health Teams, inter-professional primary care teams, and changes in home care delivery. This creates an opportunity to make the caregiving experience easier and to have caregivers share their expertise to support successful system change.



"We want to be a part of the team, but there isn't a team. They're working alongside each other but it's siloed and fragmented."

– Roundtable delegate

"Within our Ontario Health Team, we started by defining caregivers in our strategy as a priority population."

– Laura Tenhagen,
Project Management
Consultant, Sault Area
Hospital



- **Facilitate Information Sharing and improve the integration of digital health systems:** Simplify the process for caregivers to communicate and share critical information between different health care providers and specialists. This includes addressing the connectivity issues between digital health systems (eg: electronic medical records) and finding ways for caregivers to be consistently identified in these systems.
- **Expand accessibility and availability of caregiver supports:** While the availability of caregiver supports has expanded, it is not keeping pace with the growing number caregivers in Ontario and the increasing complexity of their roles. Continued investment into supports that address diverse caregiver needs and system-level approaches to caregiver screening and assessment will be needed.

“Caregivers are the thread that connects the whole system, sector to sector. Leaders in the health system need to focus on not breaking that thread, and to break down silos to support caregivers in bringing information that better supports transitions. This will reduce stress for caregivers and care teams, leading to more person-centered care. That’s the gift caregivers bring to the system”.

– Jennifer Cornell, Director of Long-Term Care, County of Grey



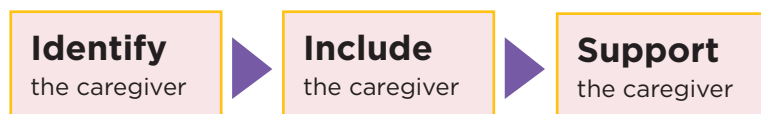
THE FUTURE STARTS NOW

The Roundtable brought to light the realities faced by caregivers, patients, and providers, grounding our discussions in the authenticity of their experiences. It also underscored the many reasons why now is the time to come together and make lasting change that recognizes the role of caregivers.

We have the evidence – and it is really clear. We know that when caregivers are involved, readmission rates go down, there are less medication errors, the patient or resident’s emotional well-being is better, patient outcomes are better, and the overall experience improves for patients, caregivers, families, and health care professionals.

We are at a turning point. Recognition that caregivers are essential is gaining momentum.

It’s time to mobilize the evidence, the learning from those who have implemented models of excellence in caregiver inclusion, and the changes taking place in Ontario’s health care system as an opportunity for a whole-system approach to integrating caregivers.



Three simple things that have the potential to transform our health care system and life for many Ontarians.

*The journey to a more connected, inclusive, and caregiver-integrated health care system is not just aspirational – **it’s achievable.***



“We know what to do with and for caregivers. We know why we must do it. Let’s work together so that caregivers can be empowered as true partners in care – at every touchpoint”
– Amy Coupal, CEO, Ontario Caregiver Organization



OUR COMMITMENT

As the Ontario Caregiver Organization, we are committed to being a leader of this transformation, and to collaborate with partners across the system to make it happen.

Caregivers, and their lived experience, will continue to be at the core of everything we do.

We are committed to:

- Keeping the voice of caregivers front and centre
- Supporting the adoption of essential care partner programs and leading practices
- Educating providers and health system partners
- Supporting and enabling caregiver engagement in planning and decision-making
- Convening cross-sector discussions
- Gathering and sharing insights to inform health system change

Let's do this together!



Contact Us

Email: partners@ontariocaregiver.ca

Ontario Caregiver Helpline

1-833-416-2273

The Ontario Caregiver Organization

Email: info@ontariocaregiver.ca

Phone: 416-362-CARE (2273) or 1-888-877-1626

www.ontariocaregiver.ca



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