A photograph of two elderly women, one with dark hair and one with white hair and glasses, both smiling warmly. The image is overlaid with a semi-transparent purple filter.

Key Moments for Caregiver Support

Considerations for Ontario Health Teams and Healthcare Organizations

March 5th 2025

Land Acknowledgement

The OCO carries out its work while acknowledging the Indigenous Peoples of all the lands that we are on today. *This land is home to many First Nations, Métis, and Inuit peoples and acknowledging reminds us that our great standard of living is directly related to the resources and friendship of Indigenous people.*

Overview for Today

1

Why caregiver support is so critical to your organization and OHT

2

First-hand caregiver insight about which interventions make a difference

3

How to implement caregiver support into your OHT model and across your organizations

4

Practical tools and resources to better support caregivers across your settings

Today's Presenters



Alison Kilbourn

Manager,
Essential Care Partner
Support Hub
The Ontario Caregiver
Organization



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Caregiver Partner
Peer Support Mentor
OCO Advisory Council
Member



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Implementation Lead,
Essential Care Partner
Support Hub
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



Improving Patient and Caregiver Health Outcomes



IDENTIFY
the caregiver



INCLUDE
the caregiver as part
of the care team



SUPPORT
the caregiver



Learning Events
and education



Tools and
resources



Collaboration,
Guidance and
Support



Connect
Caregivers to
Support

Ontario Caregivers at a Glance



4 million across Ontario, including young caregivers.



From every age group:

- 16-25 years – 14%
- 26-45 years – 35%
- 46-65 years – 36%
- 65+ years – 15%



Gender:

- Women – 52%
- Men – 46%
- Non-binary – 2%



67% are employed

Caregiver Distress



32% of caregivers say they are not coping well, majority says they feel depressed, unappreciated, resentful, lonely, and frustrated



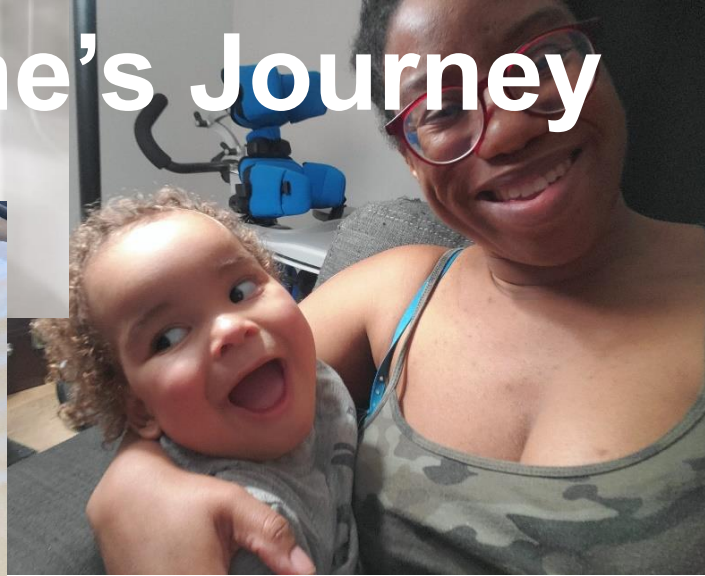
72% feel so burn out they're unsure how to continue, yet feel they have no choice but to keep going



75% are concerned they will not be able to handle their caregiving duties going forward



Katherine's Journey

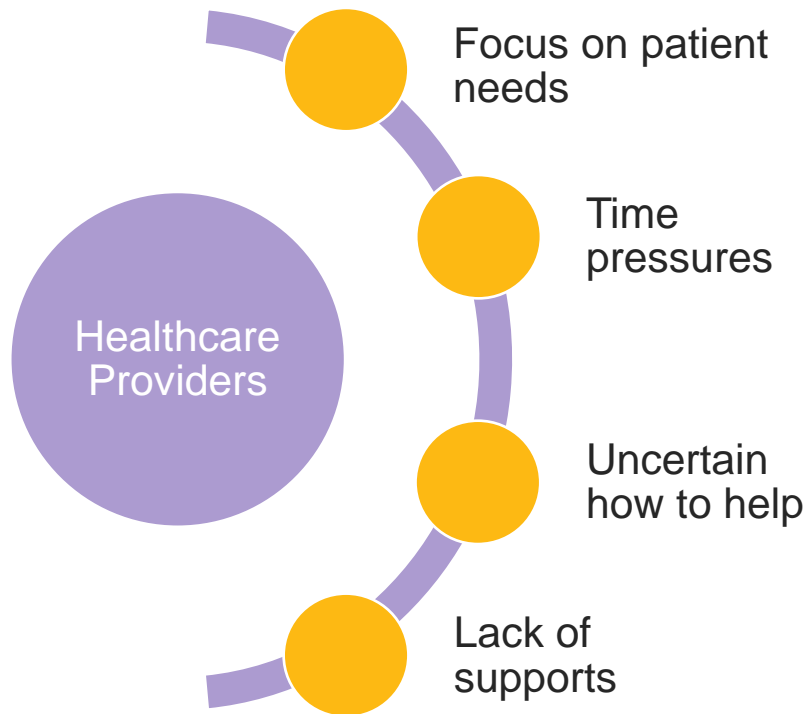
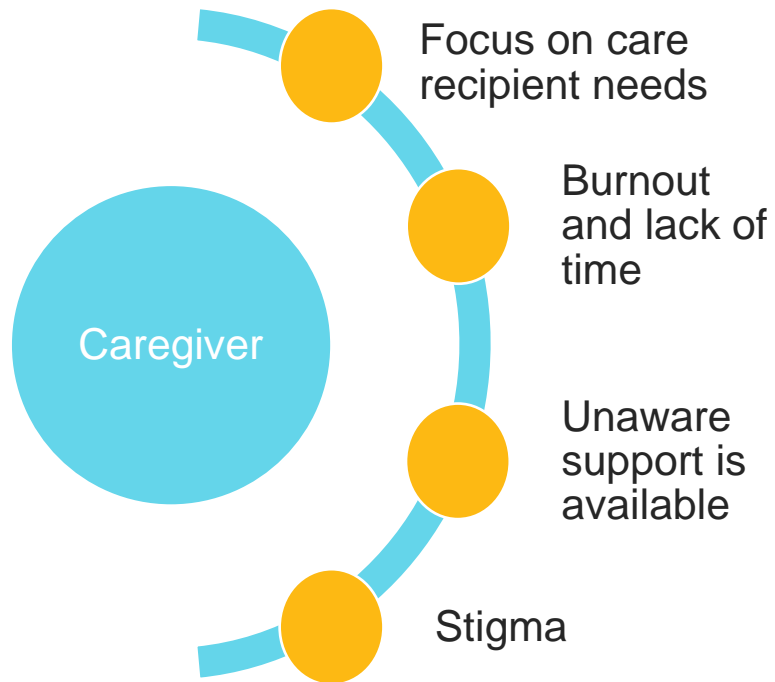


A woman with dark hair tied back, wearing a white knitted sweater and large hoop earrings, stands by a window. She is looking out the window with a thoughtful expression, holding a small object in her hands. The image has a purple tint.

Caregiver well-being is at risk

- 79% feel so tired its difficult to get things done
- 78% feel unable to take on more responsibility
- 76% unable to enjoy activities

Barriers to caregiver support

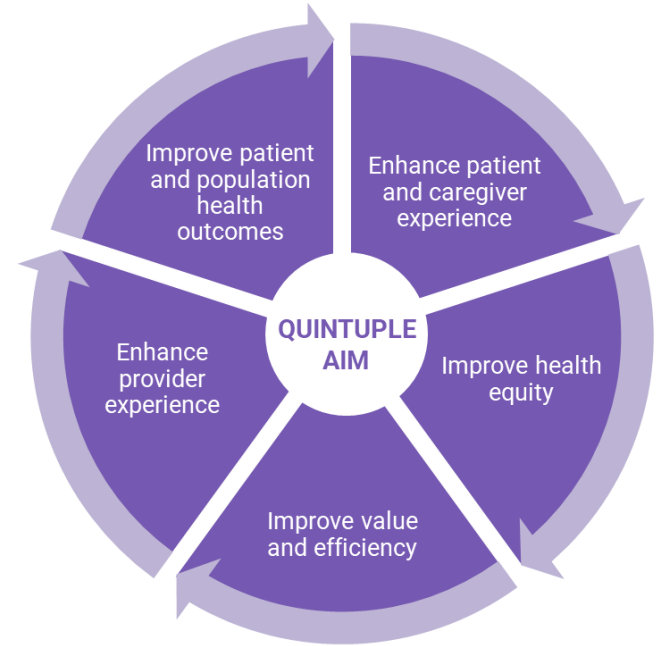


Why is caregiver well-being important to your OHT?



Caregiver well-being is critical to the Quintuple Aim

“Failure to recognize, acknowledge and support family caregivers heightens their risk of becoming “collateral casualties” of the illness, compromises their health, reduces the efficacy of the help they can provide to their relatives, and increases costs to the health and social service systems”.¹



Caregiver well-being impacts patient health outcomes



Caregiver mental health has been found to impact patient clinical and mental health outcomes²

“Caregiving is an under-recognized, under-addressed contextual factor that significantly influences the health of recipients and caregivers”³

Caregiver well-being impacts the health system

Caregiver distress can increase the use of healthcare services by care recipients:

- Delayed hospital discharge⁴
- Hospital admissions and re-admissions⁴
- Increased use of in-home services^{4,5}
- Heightened risk of ED use⁶

“Even the most well-designed and resourced hospital admission education program will fail if it doesn’t address (or at least account for) the well-being and competencies of the primary [caregiver]”⁷

Critical Role of Caregivers in our Changing Healthcare System



By 2029 there will be an additional 2.5 million more caregivers

- Next 20 years, Ontario's Population will grow by **36%**
- Millions more Ontarians are projected to be **living with chronic illnesses**
- Our province is poised to face an unprecedented **demand for healthcare**
- Increased **pressure on family caregivers**

Build capacity across your OHT to provide caregiver support

- ✓ Understand the landscape of caregiver support across your OHT
- ✓ Understand gaps in caregiver support
- ✓ Build on the assets of your OHT community and their offer of caregiver support
- ✓ Plan with the needs of caregivers embedded across your work
- ✓ Build an understanding of caregiver need across your settings

Landscape of Caregiver Support in Ontario:

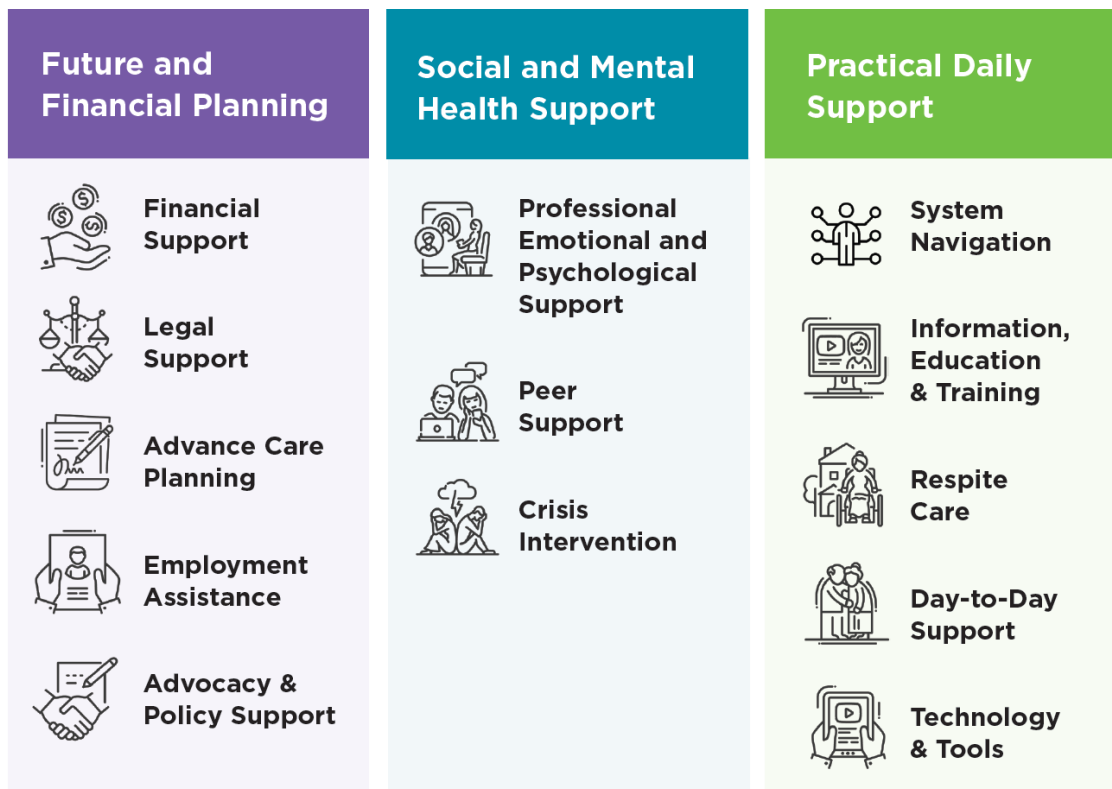
A framework to identify and categorize supports to address the diverse needs of caregivers







This resource can be used by OHTs and organizations to:

- identify types of caregiver support in their regions
- identify possible gaps in services
- explore opportunities to build caregiver support into their planning

Categories of Support



Categories of Support

Category	Types of Caregiver Support	Definition of Support	Subtypes
Social and Mental Health Support	Professional Emotional and Psychological Support 	Providing caregivers with formal assistance, counselling, and resources to cope with the emotional challenges of caregiving, such as stress, anxiety, burnout, grief and bereavement.	Individual or family counselling or therapy services
			Support groups for caregivers
			Helplines and hotlines for emotional assistance
			Caregiver wellness activities (e.g., yoga, meditation, etc)
	Peer Support	Connecting caregivers with others who are in similar	Connecting caregivers with others in similar situations
	Future and Financial Planning 	Legal Support 	Providing caregivers with legal guidance, information, and resources to address legal issues and navigate legal matters related to caregiving responsibilities.
			Power of Attorney
			Substitute Decision-Maker
	Advance Care Planning 	Helping caregivers with the process that involves making decisions about future health and personal care preferences in anticipation of a time when a person may be unable to communicate their wishes.	Human rights, etc.
			No applicable subtypes

Insights

INEQUITIES IN ACCESS TO CAREGIVER SUPPORT

- **Regional disparities:** There are inconsistencies in what supports are available across the province. Northern Ontario was specifically highlighted as having limited access to various caregiver supports.
- **Cultural and language inequities:** Indigenous and non-English speaking communities encounter difficulties in accessing support.
- **Technological challenges:** Access to technology and the associated necessary skills pose significant barriers to support utilization.
- **Cost and affordability:** Variations in service costs render some caregiver support inaccessible to individuals. The inability to afford programs limits access for many.

Top 3 most identified gaps in available support:



Respite
System Navigation
Financial

"It is sometimes difficult to find support... services in French are non-existent"
- caregiver

Insights

Caregivers want to receive this information from:	Key moments when caregivers could receive this information:
<ul style="list-style-type: none">• Local primary care teams• Doctors and nurse practitioners• Hospitals• Organizations that support individuals with specific conditions• Other partnering agencies relevant to care recipient supports	<ul style="list-style-type: none">• Upon care recipient's diagnosis• During major life transitions• When health care needs change• Signs of caregiver struggling to cope

Build Capacity across your OHT Providers to Support Caregivers



Leverage existing
local OHT
organizations
offering caregiver
support

Build in
connections to
OCO programs and
services for
caregivers





Connecting Caregivers to Support at Point of Care

Key Moments for Caregiver Support

- ✓ Opportunity to identify the caregiver
- ✓ Help determine need
- ✓ Connect them to support
- ✓ Provide them with resources or tools



Caregivers don't always self identify



"I am asking
for my dad"



"My wife's illness
is getting worse"



"My child is living
with a disability"



"My sister is sick
and going through
cancer treatment"

Understand Need



“It sounds like you are providing care to.... We can connect you to some support as well.”

“What would be helpful for you right now?”

“Do you have time to focus on your own health?”

“Did you know there are free services to support you in your caregiving role?”

“Would you like to take a moment to talk through some support options for you as well?”

Understand Need, Connect Caregivers to Support

Common Situations	What would help and what caregivers can expect
<p>Challenges with their mental health and well-being Caregivers report experiencing the following feelings:</p> <ul style="list-style-type: none">• Stress• Exhaustion or burnout• Isolation and loneliness• Confusion about who to contact• Uncertainty about the steps to take	<p>Social and Mental Health Support</p> <p>To access resources, register for programs, or receive services, caregivers (or their representatives) can click on the links provided in this document, visit the OCO website, or call the Ontario Caregiver Helpline (1-833-416-2273). A specialist will be available to guide them through the registration process and help them find available programs in their area.</p> <p>Once registered, caregivers will receive a confirmation email or a call to explain the next steps. An OCO staff member will contact them to introduce the program. If the caregiver wishes to proceed, an assessment will be conducted to officially enroll them. A letter of commitment will be sent for review, followed by an appointment with a coach. The coach will then reach out to begin one of the six sessions.</p>

The Ontario Caregiver Organization (OCO) Programs and Services:



The Ontario Caregiver Helpline

1-833-416-2273 or
ontariocaregiver.ca

Free of charge phone
support 24/7 and
live chat
(Mon-Fri 7 a.m. - 9 p.m. ET)



1:1 Peer Support and Coaching (online or by phone)

Connect with another
caregiver, share your
experiences, and
receive direct support.
Up to six 1:1 support
sessions to work-through
caregiving challenges.



Online Support Groups

Connect with other
caregivers in a
supportive environment
to share your
challenges, successes,
and concerns



Monthly Webinars (live and recorded)

OCO hosts live
webinars presented
by subject matter
experts on a variety of
timely and important
topics



The SCALE Program

An 8-week [program](#)
targeting caregiver
mental health and well
being. Providing
education, tools and
small group or 1:1
counselling sessions to
caregivers

Learn about ongoing [Caregiver Programs](#) available



FIRESIDE CHAT

With Katherine and Alison
Facilitated by Lisa

Questions?



We want to hear from you. Type your questions in the chat box!



Chat

From Me to [Everyone](#):



Please type your questions and comments in the chat-box.



Actions for your OHT

- Use the *Landscape of Caregiver Support in Ontario* resource to:
 - Understand your assets across your OHT
 - Identify gaps in caregiver support
 - Collaborate with partners to meet those gaps
- Contact the OCO for **guidance and resources** to embed caregiver support in your OHT and Organizations
- Provide the *Connecting Caregivers to Support at Point of Care* tool **to organizations across your OHT**
- Reach out to OCO to **provide education to your OHT, organization staff.**



Contact OCO to help you build caregivers in your OHT Plans

Resources for OHTs



Landscape of Caregiver Support in Ontario:

A framework to identify and categorize supports to address the diverse needs of caregivers



Connecting Caregivers to Support at Point of Care



WE'RE HERE FOR YOU.

CAREGIVER HELPLINE
1-833-416-2273

LIVE CHAT
ontariocaregiver.ca



If you're caring for someone and you need support or have care questions, call the 24/7 Ontario Caregiver Helpline: **1-833-416-2273** or visit ontariocaregiver.ca

Learn more:

- Caregiver Resources
- Caregiver Stories
- Community Supports
- Peer Support Groups
- Live Chat 7am - 9pm (Mon - Fri)
- Caregiving Publications
- Healthcare Provider Resources
- Volunteer or Partner

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THANK YOU!

Subscribe to our quarterly e-Bulletin for providers

<https://ontariocaregiver.ca/subscribe/>

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