



THE ONTARIO

caregiver

ORGANIZATION

Including Caregivers in Access and Navigation Models

CAREGIVER
INTEGRATION



A PRACTICAL GUIDE FOR OHTS



INTRODUCTION

Caregivers are extremely important to our healthcare system. Four million caregivers across Ontario provide an estimated 75% of the care in the system by caring for their family, friends, and neighbours. As healthcare settings strive to deliver better and more integrated care that looks after their whole community, it is critical to consider the needs of caregivers in navigating care for their family member, and how to ensure caregivers are connected to the supports that address their own needs.

Caregivers are not always aware or taking advantage of programs and services that are available to themⁱ, and evidence shows that well supported caregivers are more likely to provide better careⁱⁱ. Yet, conversations between providers and caregivers are centered on the care recipient, but less often on the needs of the caregiver in their role.

Supporting caregivers includes helping them to access and navigate supports they need, for both their own well-being and the wellbeing of their care recipients. In Ontario, 49% of caregivers found caregiving stressful in 2020, which is a 12% increase from 2019.ⁱⁱⁱ Further, 58% of caregivers said they were burnt out and 42% said their mental health was worse when compared to a year ago.^{iv}



[Go directly to Action Steps, Tools and Resources](#)



Caregiver burnout is a state of physical, mental and emotional exhaustion, or feeling like one can't find any hope, due to too many demands on one's energy, strength and resources and response to extended or prolonged stress.

THE EVIDENCE

Evidence shows that not supporting caregivers has an impact on both patients and caregivers:

- Caregiver distress has been found to impact clinical and mental health outcomes of patients^{vi}
- Caregiver burnout/ distress can lead to increased emergency department use^{vii,viii,ix} delayed hospital discharges , more hospital admissions and re-admissions^{xi,xii}, more long-term care placements^{xiii,xiv}, and increased use of in-home services for the person they are caring for^{xv,xvi}
- Caregivers who are not supported appropriately can have higher rates of stress and depression^{xvii}, greater loneliness, morbidity and premature mortality^{xviii}
- Caregivers are also 16% more likely than non-carers to live with two or more long-term health conditions^{xix}

As OHTs plan for new models of care and new approaches to access and navigation within their community, it is critical to consider the needs of caregivers. Inclusion of caregivers in access and navigation models and helping caregivers connect to the support they need can:

- Help OHTs achieve the quintuple aim within their community^{xx,xxi,xxii,xxiv}
- Enable caregivers to provide better care^{xxv,xxvi,xxvii}
- Prevent or address caregiver burnout and support overall caregiver wellbeing^{xxviii}
- Reduce the risk of caregivers becoming patients themselves
- Improve the health outcomes of the people caregivers are caring for
- Decrease the use of healthcare services by care recipients^{xxix,xxx,xxxi}



Susan's Caregiving Journey

“As I manage the caregiving stress that goes along with it [my father’s care], I wonder if healthcare providers across the spectrum were able to ask the question of caregivers “how are they doing” and what supports they could they give them. That would make a world of difference. I’m part of my local OHT, [and] I think what an ideal system to embed caregiver resources and supports. In the past couple of years, I have never been offered these supports, I’ve sought it out, and I wonder how many people know about the supports that are available.”

WHAT STEPS CAN OHTS TAKE TO INCLUDE CAREGIVERS IN ACCESS AND NAVIGATION MODELS?

As a starting point for assessing the OHT's readiness to embed caregiver-focused strategies into the OHT's access and navigation models, consider these questions:

- How can we better understand the need for caregiver support as we plan models of care for our priority populations?
- Have we included caregiver-specific supports, programs, and services in our inventory and pathway mapping?
- Do we have mechanisms in place to refer caregivers to support?
- How can we leverage the foundation of OHTs (collaborative partnerships and integrated care) to offer caregiver supports?
- How and when do providers from across the OHT settings interact with caregivers?
- What knowledge and understanding about caregiver needs and supports would providers benefit from?
- What are the specific needs of caregivers supporting vulnerable populations in the local OHT catchment?

After considering these questions, OHTs can take simple action steps to ensure that you have included caregivers in your access and navigation models.

These action steps are further detailed in the [Action Steps, Tools and Resources section](#).

INFORM, PLAN, ASSESS

- Consider the foundational questions listed here within the OHT's local context
- Reach out to the Ontario Caregiver Organization for advice on how local OHTs and provincial supports can be highlighted to meet the diverse needs of caregivers.
- Engage caregivers in planning and design by asking them what they need for their own health and wellbeing.
- Leverage OHT organizational partners that have expertise in caregiver support and mental health.

IMPLEMENT

- Create a section of the OHT website that is dedicated to caregiver specific resources and supports.
- Build local, regional and provincial caregiver-specific support and services into the OHT's Access & Navigation Model.
- Promote caregivers supports and access to the 24/7 Ontario Caregiver Helpline with OHT Service Providers and Partners
- Encourage your providers to offer warm transfers by phone to the Caregiver Helpline
- Assist and/ or provide information caregivers in navigating the supports and services available to them.
- Encourage OHT providers to refer caregivers to OCO programs and services.
- Offer education sessions about understanding the role of caregivers and tips and strategies to providers in access and navigation roles.

WHY IS THIS IMPORTANT TO OHTs?

OHTs are well positioned to identify caregivers, engage caregivers in their work, and connect caregivers to the support they need. The Ontario government's *Guidance for Ontario Health Teams* states that improvements in integrated care will fundamentally change how patients, families, and caregivers experience the health care system, as they will be able to access and navigate the system and be better supported as they transition from one health care provider or setting to another more easily.

Research shows that 56% of caregivers find organizing care difficult, and the majority would like one place to go for information, and for the system to be easier to navigate^{xxxiii}. Evidence shows that interventions focused on caregiver support can be effective. At the point of care, front-line providers play a key role in connecting caregivers to early supports and interventions. These can include peer support, psychoeducational and psychosocial supports, education and caregiver skills training, counselling, and respite care.^{xxxiv} The OHT plays a critical role in enabling these systems to better support caregivers in their roles.

For example, there is an opportunity for OHTs to identify and connect caregivers to and/or warm transfer them to the Ontario Caregiver Helpline. This is one way to ensure caregivers are getting connected to the supports they need to manage their health and wellbeing.



ACTION STEPS, TOOLS AND RESOURCES

The strategies in the table below include specific actions, tools, examples and resources that you can utilize to embed caregiver focused strategies into your access and navigation models:

ACTION STEP	WHAT'S IN THE TOOL/RESOURCE	TOOLS/RESOURCES
INFORM, PLAN, ASSESS		
Reach out to the Ontario Caregiver Organization for advice on how OCO programs and services for caregivers can be included in asset mapping/ inventory for your Access & Navigation model.	partners@ontariocaregiver.ca	Connect with OCO directly to learn more or set up a meeting/ information session.
Engage Caregivers in planning and design by asking them what they need for their own health and wellbeing.	<p>This link contains resources to support meaningful engagement and co-design.</p> <p>Rapid-Improvement Support and Exchange (RISE) has a number of resources to support patient, family and caregiver engagement and partnership, including a community of practice and a patient, family and caregiver group.</p>	<p>Meaningful Engagement and Design</p> <p>Review resources on the RISE web page: Resources to Support Patient, Family, Caregiver Engagement and Partnership</p>
Leverage OHT organizational partners that have expertise in caregiver support and mental health.	This is a one-page document for providers that includes a brief list of free programs and services that are available for caregivers from the OCO.	One page resource for providers
	The OCO's Care Provider Resource Centre includes tools, resources and information that can enable and support providers in helping caregivers access support and resources.	Care Provider Resource Centre

ACTION STEP	WHAT'S IN THE TOOL/RESOURCE	TOOLS/RESOURCES
IMPLEMENT		
<p>Create a section of the OHT website that is dedicated to caregiver specific resources and supports.</p>	<p>These links provide examples from different OHTs across the province who have created sections on their website dedicated to caregiver specific resources and supports.</p>	<p>Case Examples:</p> <ul style="list-style-type: none"> • Algoma OHT • East Toronto Health Partners OHT • Eastern York Region North Durham OHT • Hills of Headwaters OHT • Huron Perth Area OHT • North York Toronto Health Partners OHT • Windsor Essex Area OHT
<p>Build local, regional and provincial caregiver-specific support and services into the OHT's Access & Navigation Model.</p>	<p>These case studies provide practical examples of how caregiver voices and perspectives can be incorporated into access and navigation models</p>	<p>Case Example:</p> <p>Eastern York Region North Durham Ontario Health Team</p>
<p>Enhance and expand OHT capacity to connect caregivers to support through the 24/7 Ontario Caregiver Helpline Encourage your providers to offer warm transfers by phone to the Caregiver Helpline.</p>	<p>The Ontario Caregiver Helpline is available in English and French, with live interpretation in over 150 languages</p>	<p>24/7 Ontario Caregiver helpline</p>
	<p>These are promotional materials (i.e., posters, media clips and videos) that OHTs and providers can use to promote the OCO Helpline in their communities.</p>	<p>24/7 Ontario Caregiver Helpline promotional materials</p>
<p>Provide information to caregivers about the supports and services available to them.</p>	<p>This is a one-page document for providers that includes a brief list of free programs and services that are available for caregivers from the OCO.</p>	<p>One page resource for providers</p>
<p>Encourage OHT providers to refer caregivers to OCO programs and services.</p>	<p>This is an example of how East Toronto Health Partners OHT led by WoodGreen Community Services has partnered with Caregivers to create a Caregiver Navigation Guide.</p>	<p>Caregiver Navigation Guide-East Toronto Health Partners</p>

ACTION STEP	WHAT'S IN THE TOOL/RESOURCE	TOOLS/RESOURCES
<p>Offer education sessions, tips and strategies to providers in access and navigation roles to support the identification and referral of caregivers to support and resources.</p> <p>Note: You may also contact the OCO to explore training opportunities for providers across the OHT.</p>	<p>This Navigation Resource Guide, created as a collaborative initiative led by the Ottawa East Ontario Health Team, informs participating OHT partners on the resources and tools that exist to support their navigation efforts.</p>	<p>Navigation Resource Guide</p>
	<p>The OCO's Care Provider Resource Centre includes tools, resources and information that can enable and support providers in helping caregivers access support and resources.</p>	<p>Care Provider Resource Centre</p>

EAST YORK REGION NORTH DURHAM ONTARIO HEALTH TEAM



The [Eastern York Region North Durham Ontario Health Team \(EYRND OHT\) Access and Navigation Action Team](#) has been working to standardize navigation resources within their community and incorporated the caregiver voice and perspective in the development of their access and navigation model.

The EYRND OHT engaged caregivers early in the planning and design of their model. As a result, they have been able to increase knowledge and capacity within their community, including how and when to refer caregivers to caregiver specific supports. For example, the Ontario Caregiver Organization's [24/7 Ontario Caregiver Helpline](#) is included as a point of contact for caregivers so they can receive caregiver-oriented service and be connected to caregiver-specific supports offered within the EYRND area and province-wide.

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