



THE ONTARIO

caregiver

ORGANIZATION

Landscape of Caregiver Support in Ontario:

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



BACKGROUND

In Ontario, caregiver stress and burnout is on the rise, the financial impact of caregiving is growing, and working caregivers are struggling to balance work and care responsibilities (Spotlight, 2023). Caregiver supports help. Evidence suggests that interventions offering caregivers support and education reduces stress and burnout and improves the patient and caregiver experience.

There are 4 million caregivers in Ontario; ordinary people who provide physical and emotional support to a family member, partner, friend or neighbour. Caregivers need support. The Ontario Caregiver Organization recently conducted a project to better understand the landscape of caregiver support across the province. One of the project's goals was to provide information for healthcare organizations including Ontario Health Teams so they are better positioned to build caregiver support into their health system planning. The project defined and categorized 13 types of support available to caregivers, gathered through an environmental scan and engagement with key informants, including caregivers.



This summary resource can be used by OHTs and organizations to identify types of caregiver support in their regions, possible gaps in services, and explore opportunities to build caregiver support into their access and navigation models and service plans.

UNDERSTANDING CAREGIVER SUPPORT

Caregiver support refers to the various services, resources, and assistance provided to individuals who are taking care of someone, or supporting someone with health conditions, disabilities, or age-related needs. These supports aim to help caregivers manage their responsibilities more effectively, reduce stress, and enhance the well-being of both the caregivers and the individuals receiving care.

RAISING AWARENESS AND PROACTIVELY SUPPORTING CAREGIVING NEEDS

Proactively supporting caregivers by providing information on available resources upfront is critical, rather than waiting until a crisis or burnout state. Services should cater to both care recipient and caregiver simultaneously, as supporting one aids the other. Ensuring that caregivers receive support for both their own well-being, in addition to the tools and resources they need to improve the care they provide to the person they support.



“I will say as a caregiver, I didn’t know half of these supports were available”.
- caregiver

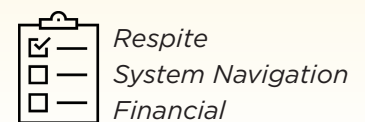


| Caregivers want to receive this information from: | Key moments when caregivers could receive this information: |
|--|--|
| <ul style="list-style-type: none"> • Local primary care teams • Doctors and nurse practitioners • Hospitals • Organizations that support individuals with specific conditions • 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 |

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:



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

*“There are many constraints, the pricing, the financial barriers coming with the respite are immense and it’s not available to me”
- caregiver*



EXPLORING CATEGORIES OF SUPPORT

Support can be organized by category and by subtype of support including region, type of condition, age of care recipient, language/ethnicity, cost/no cost and through diverse service providers. These 13 categories can be compiled into three groups: Future and Financial Planning, Social and Mental Health Support, and Practical Daily Support.



























| Future and Financial Planning | Social and Mental Health Support | Practical Daily Support |
|--|---|---|
|  Financial Support |  Professional Emotional and Psychological Support |  System Navigation |
|  Legal Support |  Peer Support |  Information, Education & Training |
|  Advance Care Planning |  Crisis Intervention |  Respite Care |
|  Employment Assistance | |  Day-to-Day Support |
|  Advocacy & Policy Support | |  Technology & Tools |

TABLE 3: CATEGORIES OF CAREGIVER SUPPORT WITH ASSOCIATED DEFINITION AND SUBTYPES

| Category | Types of Caregiver Support | Definition of Support | Subtypes |
|---|---|--|--|
| Future and Financial Planning | Financial Support  | Assisting caregivers in managing the financial aspects of caregiving, including accessing benefits, financial aid, and resources to alleviate financial strain. | Tax Credit (CRA) (Disability tax credit, caregiver credit) |
| | | | El Caregiving benefits |
| | | | Ontario Gov Supports (MCCSS) (e.g., Special Services at Home, Assistance for Children with Severe Disabilities, DSO, Passport Program) |
| | | | Caregiver Grants |
| | 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 |
| | | | Human rights, etc. |
| | 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. | No applicable subtypes |
| | Employment Assistance  | Supporting caregivers in balancing their caregiving responsibilities with employment by providing flexible work arrangements, employment assistance programs, and resources for working caregivers. | Flexible work arrangements or leave policies for employed caregivers |
| | | | Employee Assistance Programs (EAPs) |
| Advocacy & Policy Support  | Advocating for caregivers' rights, needs, and interests at the individual- and systems- level and providing support to navigate relevant policies and systems impacting caregiving. | <p>Individual-level support provides support to caregivers to advocate for their rights and needs on a personal-level</p> <p>Systems-level support focuses on addressing issues at a broader-level by advocating for policy changes, systemic reforms, or improvements to institutional structures</p> | |

| 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 caregiving situations to provide mutual support, share experiences, and offer encouragement. | Connecting caregivers with others in similar situations Online forums and communities |
| | Crisis Intervention  | Providing caregivers with immediate support, assistance, and resources in times of crisis, emergencies, or unexpected challenges. | Immediate support in emergencies or crisis situations (e.g., in-home visit, short-term crisis bed) Emergency response plans |
| Practical Daily Support | System Navigation  | Helping caregivers understand service and healthcare options, access services, complete forms, and navigate the social services/healthcare system effectively to ensure optimal care for their care recipient. | Home and community care navigation Healthcare navigation Transition Support (e.g., moving from hospital to LTC/home) Developmental services navigation |
| | Information, Education & Training  | Offering caregivers access to information and opportunities for learning, skill development, and training to enhance their caregiving knowledge, competence, and effectiveness. | Resources specific (articles, webinars, workshops) to the medical condition or disability General resources (articles, webinars, workshops) on caregiving Resources specific to particular population groups (e.g., race/ethnicity, religion, LGBTQ+, children/youth, etc.) |
| | Respite Care  | Providing caregivers with temporary relief or time away from their caregiving responsibilities to rest, rejuvenate, and attend to their own needs. | In-home respite Adult day programs Daycare/before and after school care Residential respite |
| | Day-to-Day Support  | Offering caregivers assistance with day-to-day tasks and activities involved in caregiving, such as meal preparation, transportation, personal care, and household chores. | Medication management Transportation Meals Chores/tasks |
| | Technology & Tools  | Offering caregivers access to assistive technologies, tools, and resources designed to support them in their caregiving roles and enhance the quality of care provided. | Communication support Role support (e.g., online shopping, reminders/alerts, home automation devices, apps) |

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

