# Supporting Caregivers Supports Patients: The Critical Role of Primary Care in Preventing Caregiver Burnout

The Ontario Caregiver Organization in partnership with the Primary Care Collaborative November 24, 2022



# Today's Learning Objectives

Identify the caregiver role as it relates to patient care and health outcomes



Describe the impact of caregiving on caregiver well-being and capacity to continue in their role

Identify barriers to addressing caregiver burnout and apply strategies to mitigate those barriers

Use practical tools and action steps to support caregivers and prevent burnout

Recall programs and services that are available for all caregivers across Ontario offered by The Ontario Caregiver Organization.



### Today's speakers

**Alison Kilbourn** – Project Lead, Strategic Partnerships & Innovation, The Ontario Caregiver Organization

**Bhavini Patel** – Caregiver, Advisory Council Member, The Ontario Caregiver Organizaton

Chantelle Mensink – Nurse Practitioner, New Vision Family Health Team

Albesa Aliu – Health Promoter, Rexdale Community Health Centre

**Dr. Javed Alloo** – Clinical Lead, Primary Care Integration, Ontario College of Family Physicians



# **Speaker Disclosures**

Relationships with financial sponsors (including honoraria) and conflicts of interest

- Alison Kilbourn: Employee of The Ontario Caregiver Organization; No conflicts of interest to declare in this presentation.
- **Bhavini Patel**: Patient Representative Quality and Program Effectiveness Committee, Trillium Health Partners (Non Director, Board of Directors); Advisory Committee Member, Health Mentor, Facilitator Centre for Advancin Collaborative Healthcare & Education (CACHE), University of Toronto; Advisory Council Member, Ontario Caregiver Organization, receiving honorarium from Ontario Caregiver Organization; No conflicts of interest to declare in this presentation.
- **Chantelle Mensink**: Employee of New Vision Family Health Team; No conflicts of interest to declare in this presentation.
- Albesa Albui: Employee of Rexdale Community Health Centre; No conflicts of interest to declare in this presentation.
- Dr. Javed Alloo: Ontario College of Family Physicians, Ontario Medical Association, Centre for Effective Practice, Centre for Addictions and Mental Health, Trillium Health Centre, Memotext, Canadian Partnership Against Cancer, Mental Health Commission of Canada – Honoraria, Consulting, Employed; CIHR, U of T – Research Grants; Canada: Novo Nordisk, Boehringer Ingelheim, Lupin, Astra Zeneca – Advisory Boards; No conflicts with content in this presentation.





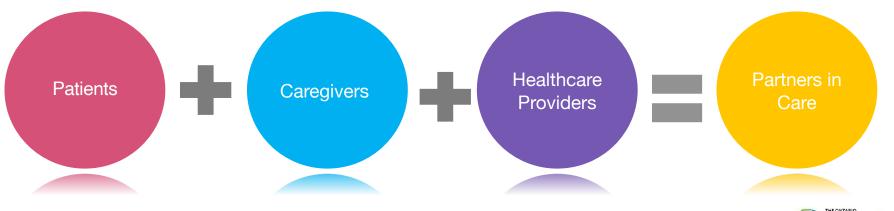
## OUR PURPOSE

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

### Caregivers are Critical to our Health Care System



### 4 million caregivers across Ontario provide an estimated 75% of the care in the system



# Caregiving has an impact on **Caregiver Health**

Higher rates of loneliness<sup>1</sup>, stress and depression<sup>2</sup>

16% more likely than non-carers to live with 2 or more long-term health conditions<sup>3</sup>

"Distressed caregivers experience a myriad of adverse outcomes, including deteriorations in mental and physical health, disruptions in social and family relationships, and increased risk of death."<sup>4</sup>  Vasileiou, K., Barnett, J., Barreto, M., Vines, J., Atkinson, M., Lawson, S., & Wilson, M. (2017). Experiences of Loneliness Associated with Being an Informal Caregiver: A Qualitative Investigation. Frontiers in psychology, 8, 585.

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- Stall, Nathan. We Should care more about Caregivers. CMAJ March 04, 2019 191 (9) E245-E246; DOI: <u>https://doi.org/10.1503/cmaj.190204</u>
- Centers for Disease Control and Prevention. https://www.cdc.gov/aging/publications/features/lonely-older-adults.html

## Caregiver well-being has an impact on **Patient Health Outcomes**

Well-supported caregivers are more likely to provide better care<sup>1</sup>

Caregiver mental health has been found to impact patient clinical and mental health outcomes, given the heavy reliance on caregivers for managing patient symptoms and providing support<sup>2</sup>

Caregiver burnout can lead to patients requiring ER visits and/or unnecessary hospital admissions<sup>3,4</sup> 1. Canada, a Caring Society: Action Table on Family Caregivers Informed dialogue, leading to concrete action for all Canadians NOV 2013

http://www.ccanceraction.ca/wp-content/uploads/2014/12/Family-Caregivers-Meeting-Report.pdf

2. Shin, J. Y., & Choi, S. W. (2020). Online interventions geared toward increasing resilience and reducing distress in family caregivers. Current opinion in supportive and palliative care, 14(1), 60–66. https://doi.org/10.1097/SPC.00000000000481 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6996606/

3.American Society on Aging(2020).https://generations.asaging.org/caregivershospitalizations-readmissions

4.Claire K. Ankuda MD, MPH,Donovan T. Maust MD, MS,Mohammed U. Kabeto MS,Ryan J. McCammon MA,Kenneth M. Langa MD, PhD,Deborah A. Levine MD, MPH (August 2017). Association Between Spousal Caregiver Well-Being and Care Recipient Healthcare Expenditures. https://doi.org/10.1111/jgs.15039

### Social Determinants of Health + Caregiving

#### **Caregiving Context**

Living situation/proximity, setting, financial resources, community resources and characteristics

#### **Caregiving Characteristics**

Length of caregiving, carer experience and skills, carer communication and advocacy skills, motivation, relationship quality, strength of network, other family obligations

#### Person receiving Care

Relationship, disease/condition, functional/cognitive status, abilities and strengths, health care needs

#### Carer

Age, gender, sexual orientation, cultural background, race/ethnicity, employment, religious affiliation, socio-economic status, physical and mental health

Image from: Heather M. Young and Janice F. Bell and Robin L Whitney and Ronit A Ridberg and 9 | OCO | November 2022 Sarah C. Reed and Peter P. Vitaliano, Social Determinants of Health: Underreported Heterogeneity in Systematic Reviews of Caregiver Interventions, The Gerontologist, 2020 (60, pgs 14-28).

# COVID-19 has increased caregiver burn-out in Ontario

61%



of caregivers find caregiving stressful overall

of caregivers feel lonely, isolated of caregivers feel burnt out

58%





### Primary Care – Ideal Setting for Connecting Caregivers to Support

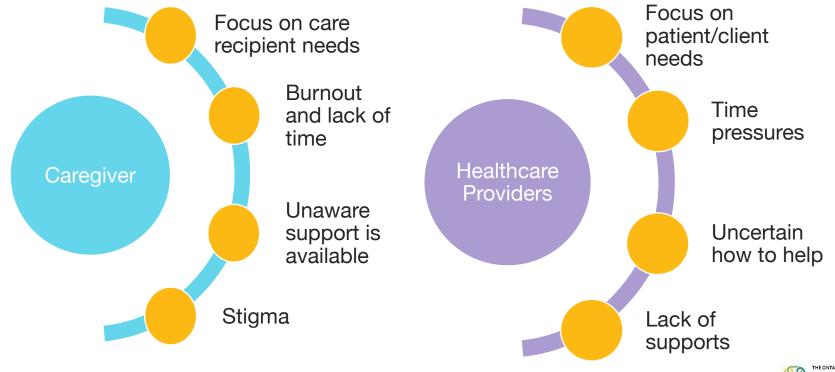


- Primary care is the ideal context for reaching most caregivers
- Typically, primary care is the earliest point of contact
- Collaborative, integrated care models work well in primary care settings to meet caregivers' needs

Source: Parmar, J, Anderson, S, Abbasi, M, et al. Support for family caregivers: A scoping review of family physician's perspectives on their role in supporting family caregivers. Health Soc Care Community. 2020; 28: 716–733



### **Barriers to Caregiver Support**





# Bhavini's story

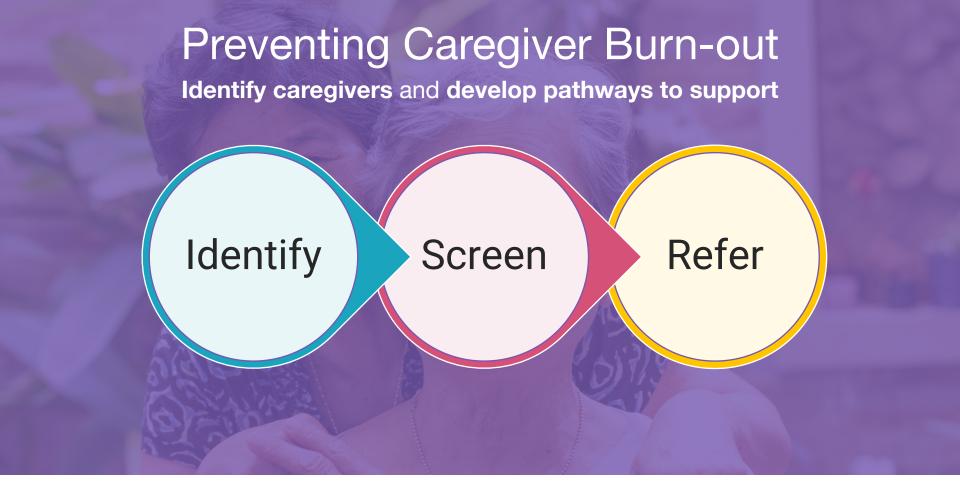






## **Experience from Primary Care Settings**







# Opportunities for Caregiver Engagement

Upon new diagnosis for a patient (e.g., Dementia, Parkinson's)

Care recipient positive screen for frailty

Significant change or worsening of patient symptoms

Significant change in family/social structure

Signs of caregiver distress, burn-out



### **Developing Pathways to Support: Time to Talk**

#### **Tips on Engaging Caregivers**

- Ask caregivers how they are doing
- Include caregivers as part of the healthcare team
- Share what's happening & what to expect next
- Encourage caregivers to accept help
- Encourage caregivers to visit **ontariocaregiver.ca** or call the 24/7 helpline at **1 833 416 2273**
- Encourage caregivers to talk to someone about their feelings
- Re-visit this conversation throughout their journey



Time to Talk

The Time to Talk Toolkit has been adapted by the Ontario Caregiver Organization, and was developed by Connecting the Dots for Caregivers, a partnership between six healthcare organizations in Huron Perth, and one of The Change Foundation's Changing Care projects.



### **Time to Talk Poster**



Being a family caregiver often means you have less time to care for your own needs. If you're feeling overwhelmed in your caregiving role, speak to your health care team.

OCO November 2022

18

### Time to Talk Pamphlet

Time to Talk

**66** I'm honoured to care for my mom. I don't know where to find the information I need. 33 Being a family caregiver often means you have less time to

1.833.416.2273.

but I'm tired and overwhelmed.

care for your own needs. If you're feeling overwhelmed in

your caregiving role, speak to your health care team.

For more information about caregiving and to access programs and services that can support you in your programs and services that can support you in your role visit **ontariocaregiver.ca** or call our 24/7 helpline at



CAREGIVER

on't know what to say. It ly it happened...It was not Alzheimers"

althcare team.



wait until you reach a point where you can no longer cope. If you are a caregiver and feeling overwhelmed in your role, please reach out to a member of your

SIGNS YOU MAY BE EXPERIENCING CAREGIVER BURNOUT

n needs because life is dominated by caregiving

pelmed or helpless, and possibly hopeless oing or eating patterns and/or the excessive

If you are experiencing any of the following, you may be I signs of caregiver burn-out. Please speak to a

axing even when help is available

energy and exhaustion

of tremendous guilt sick, feeling unwell, anxious



Annabis, and/or prescription medications WHAT CAN YOU DO? It's Time to Talk. Don't

#### Free Caregiver Programs and Services for Caregivers from OCO



#### Caregiver Helpline – 1-833-416-2273

This toll free, confidential helpline is available for caregivers 24/7 by phone or Mon-Fri 9am -7pm by chat.

#### **Peer Support**

OCO offers two different peer support programs. Our Online Support Groups for Caregivers and our 1:1 Peer Support Program.

#### SCALE



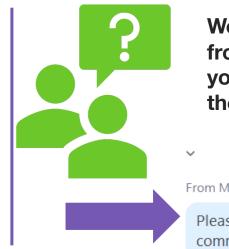
An 8-week program targeting caregiver mental health and well being. Providing education, tools and small group or 1:1 counselling sessions to caregivers.

#### Education

OCO offers monthly webinars, toolkits, eLearning, tip sheets, podcasts and so much more on our website.



### 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.



# 3 Ways to Make an Impact

During appointments, identify caregivers and ask how they are doing

Connect caregivers to supports and services by providing OCO materials

Post Time to Talk posters in your office
and/or on screens in your waiting
room



### Connect with us!

Ontario Caregiver Helpline: 1-833-416-2273

www.ontariocaregiver.ca

@CaregiverON



Explore OCO's <u>Care Provider</u> <u>Resource Centre</u> for tools and resources to support caregivers



Sign up to receive OCO's <u>Partners in Care e-Bulletin</u> for providers

Alison Kilbourn Project Lead, Strategic Partnerships & Innovation <u>alisonk@ontariocaregiver.ca</u>

