



Circle of Care
Sinai Health

Don't Confuse Courage With Wisdom: Addressing Caregiving Burnout and Burden

Patricia Wendy
Elinor Gal

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**“There are only four kinds of
people in the world:
Those who have been caregivers
Those who are currently caregivers
Those who will be caregivers
Those who will need caregivers”**

Rosalynn
Carter

Case Scenario: Lynn

- 55 y/o
- Type 2 diabetes, asthma, depression
- Primary school teacher
- Married to Paul (65 y/o), diagnosed with mild Alzheimer's disease, falls, confused and unable to adhere to complex drug regimen
- No children or family available
- Lynn had to start working part-time to look after Paul as resources are limited and income has been reduced
- Lynn is unsure where to turn to get information and support

Who are Caregivers?

Family members, friends or neighbours who provide care for someone without pay, due to frailty, palliative care, long term illness, long term recovery from accident or surgery, degenerative disease, physical or mental disability or old age related disorder.



In Canada...

Family caregivers assist family members, friends and neighbours with long-term health problems, disabilities or functional limitations. In Canada, in 2018, there were



1 in 4 Canadians aged 15+ (26%) were caregivers in 2018.

7.8 million caregivers

Caregivers' time is valuable

Caregivers provided

5.7 billion hours

of unpaid care. Time spent caregiving reduces opportunities for education and employment, connecting with family and friends and maintaining caregivers' own well-being.



The work of family caregivers supports the social connections, dignity and well-being of those they care for. The annual economic value of family care work is

\$97.1 billion

2.8 million FTE

That's the number of full-time equivalent (FTE) workers it would take to replace the 5.7 billion unpaid hours that family caregivers provide. Without caregivers' care work, home, community and long-term care would collapse.

Caregivers' contributions to Canadian society are significant

Caregivers' contributions to the Care Economy represent:

4.2%

of Gross Domestic Product

32.2%

of national expenditures on health care

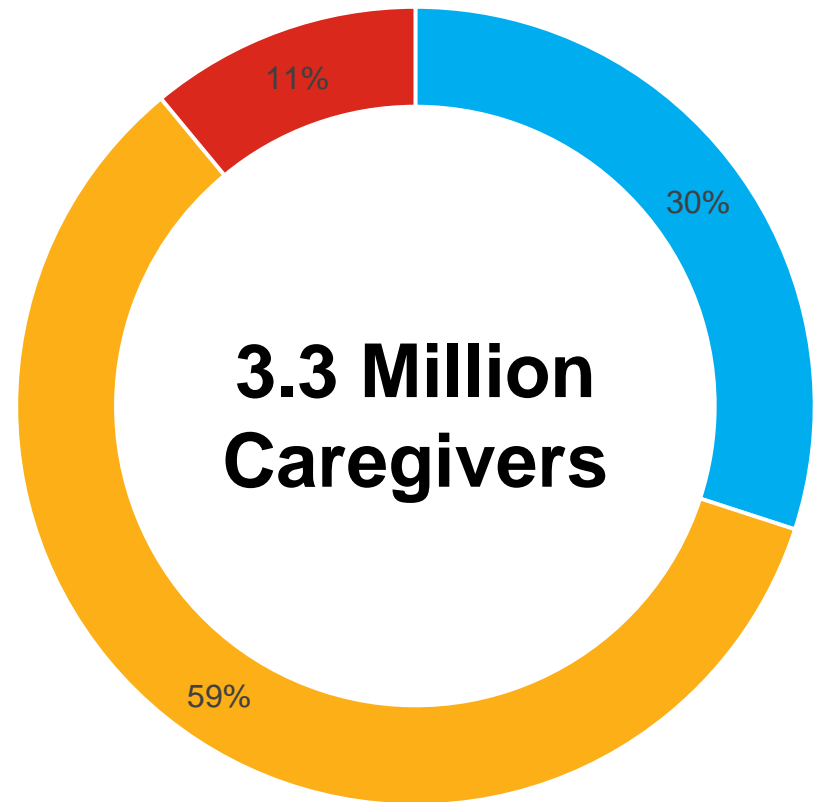
> 3 times

national expenditures on home, community & long-term care

Statistics Canada's 2018 General Social Survey on Caregiving and Care Receiving

In Ontario...

- Majority of caregivers are employed; they are married or partners, and parents (Sandwich Generation)
- 82% care for one person, usually an older family member, often a parent.
- Almost 1 in 5 are caring for more than one person
- 36% of caregivers are supporting someone with problems associated with old age or frailty.
- 30% are visible minorities
- Over 80% care for the person at home.



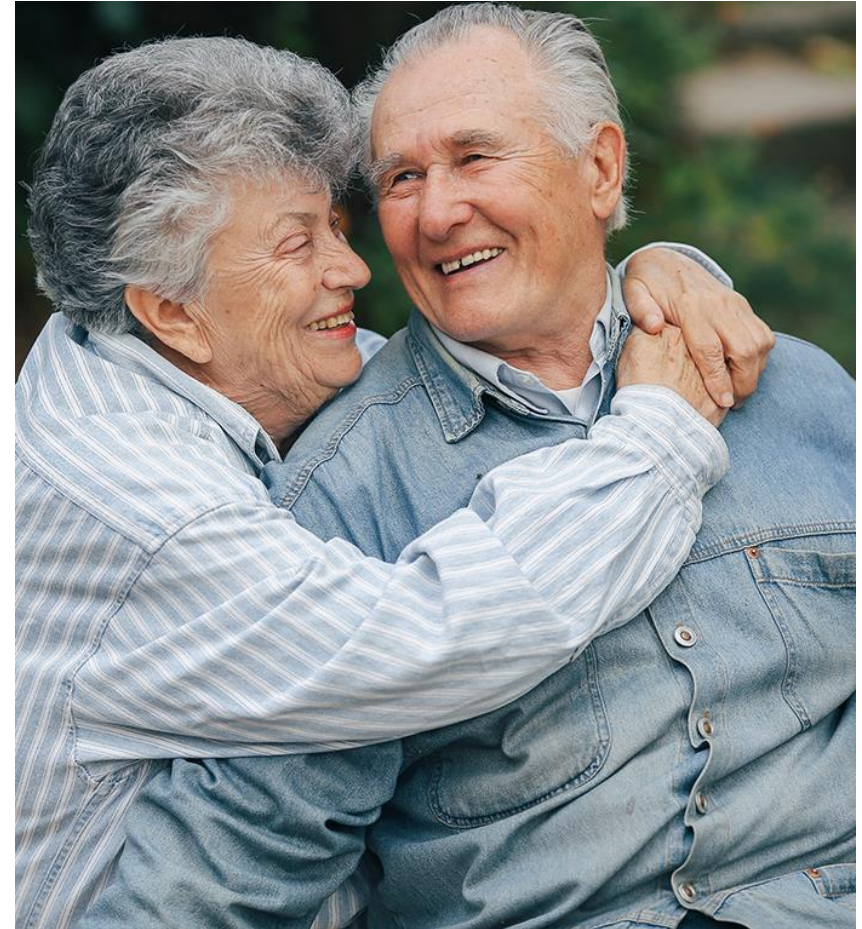
■ Under 35 ■ 36-64 ■ 65+

“Spotlight on Ontario’s Caregivers Report”, Ontario Caregiver Organization, 2020,2021.

What Caregivers Do

An unlimited array of assistance, more complex and for a longer period:

- Providing emotional support
- Escorting to medical appointments
- Managing medication, test results and papers
- Providing physical care (e.g. feeding, dressing and bathing)
- Coordinating care and services
- Keeping family and friends informed
- Making legal and financial arrangements



Who Are They Caring For?

- 50% provide care to their own parents and in-laws
- Approximately 25% care for extended family members such as grandparents, siblings or other relatives
- 1/10 care for a spouse or partner; 1/20 care for children
- People living with old age or frailty, dementia/Alzheimer's
- Children with a mental illness, developmental or physical disability
- Adults dealing with health conditions such as back problems, chronic long term pain, recovery from surgery, physical disability, cancer or mental illness

"Spotlight on Ontario's Caregivers Report", Ontario Caregiver Organization.

Their Contribution to Society

- Supplement the government-funded service
- Contribute to Ontario's health care system by providing care to someone before and after a range of treatments
- Enable people to stay and age in their home
- Average 20 hours per week caring for someone; 25% caregivers spend 40 hours per week
- 28.5 billion dollars per year

Caregiving has an impact on caregiver health and wellbeing

- Higher rates of loneliness, stress and depression
- More likely to live with 2 or more long-term health conditions
- Distressed caregivers may experience adverse outcomes, including deteriorations in mental and physical health, disruptions in social and family relationships, and increased risk of death
- Of those caregivers who spend more than 10 hours a week, 68% say they can only take a break occasionally or never
- 1 in 3 say they have no one to ask for help
- Those caring for child or spouse are most stressed overall

Caregivers report that caregiving has affected their ability to advance in their jobs. Some have used their personal savings to survive, quit their job to care for loved ones, or have to take 1 - 2 months off work to provide care.

*“Spotlight on Ontario’s Caregivers Report – November 2021”,
Ontario Caregiver Organization.*

COVID-19 and Caregiving

- Increased social isolation
- Difficulty accessing doctors and/or other healthcare professionals
- Delayed/cancelled appointments require more time and effort in rescheduling
- Difficulty managing care recipient's anxiety due to COVID-19
- Finding services and keeping themselves and their families safe
- Caregivers have taken on responsibilities that would otherwise go to a personal support worker or nurse
- Increased caregiver burden



Factors that Contribute to Caregiver Stress



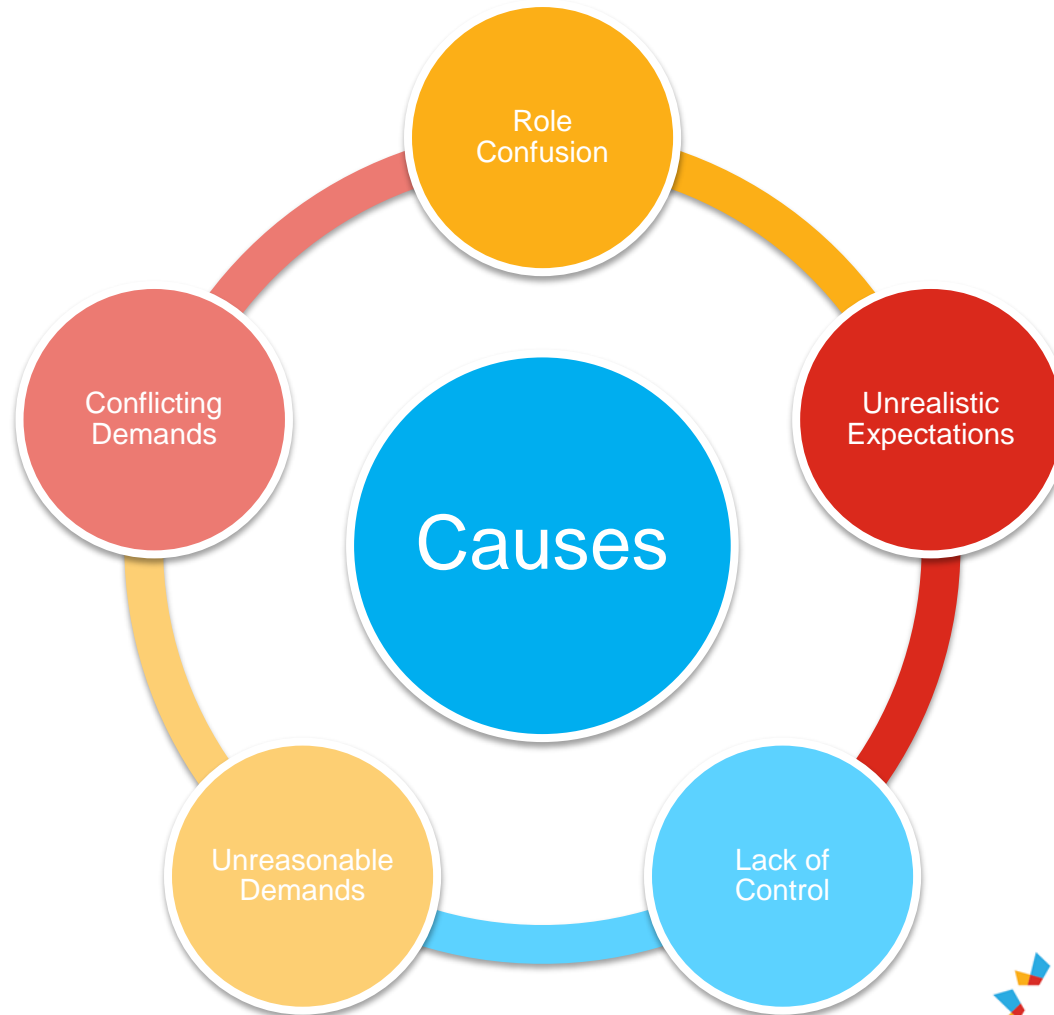
What is Caregiver Burden and Burnout?

Some caregivers may feel a physical and/or a mental strain/**burden** by the heavy responsibilities that are involved in the role of caregiving. At that point, they may perceive that “there is nothing more to give”.

Caregiver **burnout** is caused by long-term stress that impacts the physical and emotional state, and causes mental exhaustion. It may be accompanied by a change in attitude, from positive and caring, to negative and unconcerned. Burnout can occur when caregivers don't get the help they need, or if they try to do more than they are able, physically or financially.



Causes of Caregiver Burnout



Common Signs of Caregiving Burnout



Easily flustered
or frustrated



Forgetful or foggy



Quick to anger



Extremely tired



Anxious or depressed



Uninterested in things
they used to enjoy

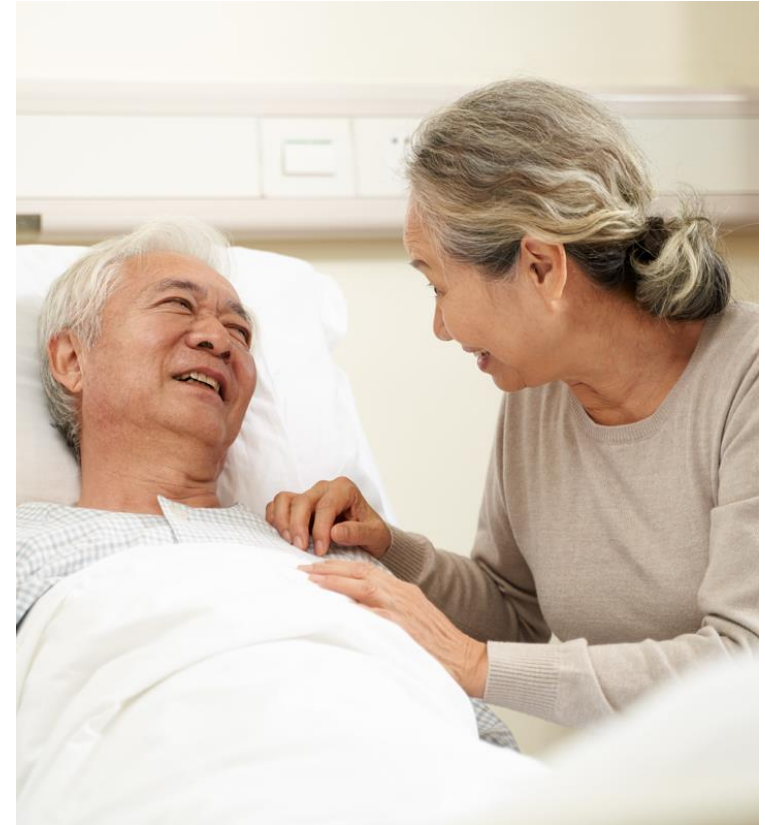


Hopeless or helpless

Why is This Important ?

Caregiver well-being has an impact on patient/client health outcomes:

- Well-supported caregivers are more likely to provide better care ⁽¹⁾
- 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 ⁽²⁾
- Caregiver burnout can lead to patients requiring ER visits and/or unnecessary hospital admissions ^(3,4)
- Caregiver stress can lead to potential elder abuse/neglect



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.0000000000000481> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6996606/>

3. American Society on Aging(2020).<https://generations.asaging.org/caregivers-hospitalizations-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>

Caregiving and Elder Abuse

Studies show that stressed caregivers may engage in some form of abuse.

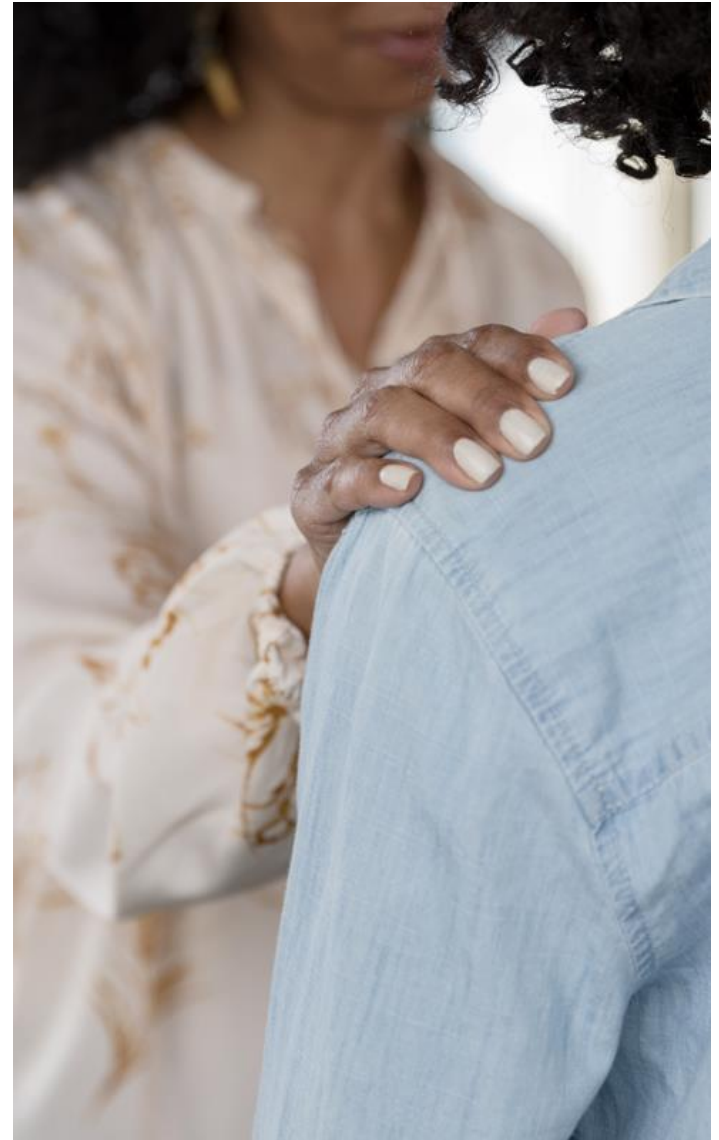
Predictive factors of caregiver abuse include:

- Depression
- Poor problem-solving skills
- Financial difficulties
- Perception of social isolation and lack of support
- Amount of care required
- Quality/history of relationship between caregiver and care recipient
- Disruptive behaviours from care recipient
- Co-habitation
- Caregivers' low self-esteem



Ways to Support Caregivers

- ✓ Ask caregivers how they are doing
- ✓ Identify caregivers and include them as part of the healthcare team
- ✓ Tell caregivers what's happening and what they can expect next
- ✓ Encourage caregivers to accept help
- ✓ Encourage them to talk to someone about their feelings
- ✓ Re-visit this conversation throughout their journey



Coping Strategies for Caregivers

Reasonable expectations

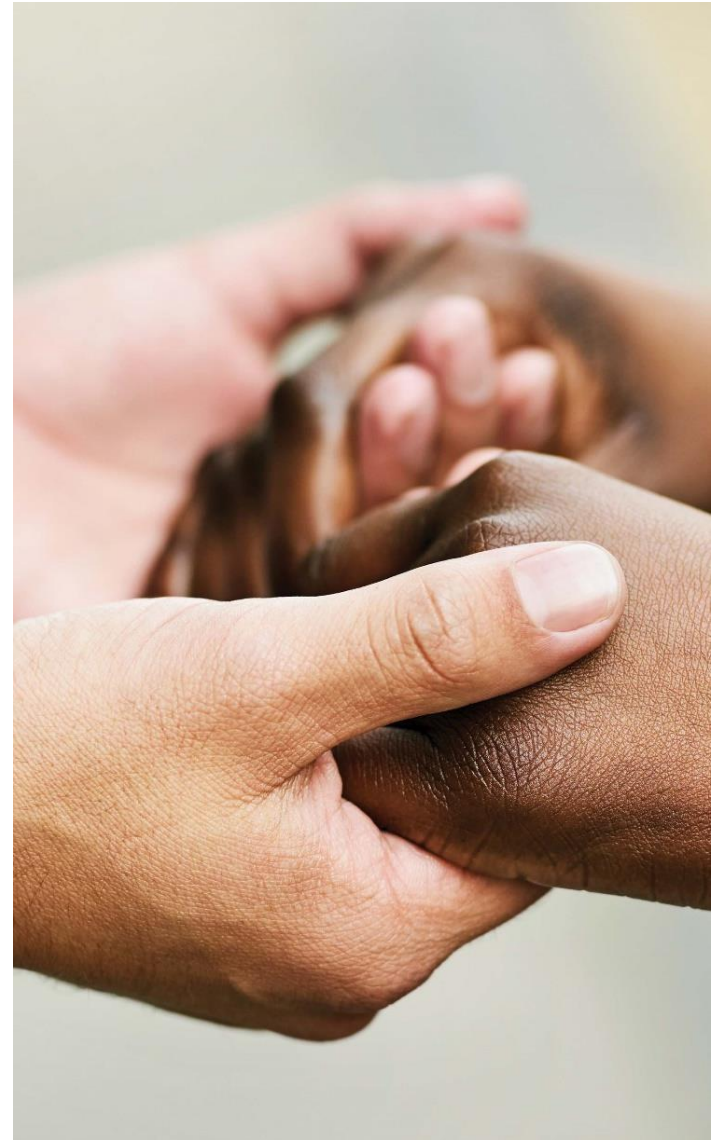
Plan

Use the help of others

Exercise

Self care

Positive self-appraisal



Caregiver Supports

- Financial Benefits
- Respite care
- Short stays
- Day Programs
- Home care supports and other community resources (i.e. MOW, transportation)
- 24/7 Caregiver Helpline
- Educational resources, webinars and e-learning opportunities
- Support groups and counseling
- Toolkits for Caregivers
- Advanced Care Planning
- Palliative and End of Life care
- Virtual Healthcare
- System navigation and coordination of services

Helpful resources for Caregivers

- ONTARIO CAREGIVER HELPLINE: 1-833-416-2273
- Circle of Care: 416-635-2860 or www.circleofcare.com
- Ontario Caregiver Organization – OCO: www.ontariocaregiver.ca
- Seniors Crisis Access Line (Toronto) 416-619-5001
- Telehealth Ontario after hours Support for Caregivers of people with dementia 1-866-797-0000 -Trained registered nurses offer support, advice and referrals 24/7.
- Central Community Care Access Centre information and Referral
<http://centralhealthline.ca>
- Toronto Seniors Helpline - 416-217-2077 or
<https://torontoseniorshelpline.ca/>

Questions?

Contact Information

Patricia Wendy

pwendy@circleofcare.com

416-635-2860 ext. 499

Elinor Gal

egal@circleofcare.com

416-635-2860 ext. 139

