



Young Caregivers: A Hidden Population

Kathleen Slemon, Program Lead- Ontario Caregiver Organization

Goals and Objectives

Goal:

Provide frontline staff with knowledge and resources pertaining to a hidden sub-population of children and youth, known as Young Caregivers.

Learning Objectives:

1. Gain a general understanding of the young caregiver population in Canada, including possible benefits incurred and implications faced
2. Acquire practical methods of supporting young caregivers in your practice.

The More You Know...

How would you define a “young caregiver”?

Do you think you know any young caregivers?

Who are they?

- “Young Caregivers” are children, youth, or young adults who are responsible for providing support and/or care to a person close to them.
- They may be supporting a loved one who is living with an illness, disability, mental health challenge, or substance use difficulty.
- The person needing care may be one of the following: Parent, Sibling, Grandparent, Partner, Friend, and more.

Did you know...

1.25 million Canadian youth between the ages of 15 to 24 provided unpaid caregiving.

There are many more left out of the statistics, as there is no data for young caregivers under the age of 15.

Who are they?

- The age that one begins providing care, as well as the responsibilities that they are required to take on, is dependent on each distinct circumstance.
- Being a caregiver does not discriminate; these children and youth can be of any age, ethnicity, socioeconomic status, etc.
- The factors impacting one's caregiving role includes the type of illness and its chronicity, the availability of external supports (ex: respite services), and the developmental stage of the caregiver.

What kinds of support do young caregivers provide?

- According to Buck & Harkness (2014), young caregivers provide 3 types of support
 - Maintenance
 - Monitoring
 - Management
- Young caregivers may provide emotional support, support around the house, childcare, translating, income support and more.



“I don’t know what a teenage life is like ... but I wouldn’t want to change anything” (Female Young Caregiver, age 17).

Benefits of unpaid caregiving

A study of 15 youth (ages 15 to 18 years-old) found that caregiving provided:

- Opportunity to build closeness, instill feelings of pride and competence and foster empathy and compassion
- Opportunity to acknowledge the important role that they play in order to support their family unit.
- Helped to provide early expertise about care-based professions, which motivated their future career aspirations.

(Stamatopoulos, 2017)

Young Caregiver Penalty

The “Young caregiver penalty” is a term coined to describe the hardships incurred by children and youth providing ongoing and substantial care.

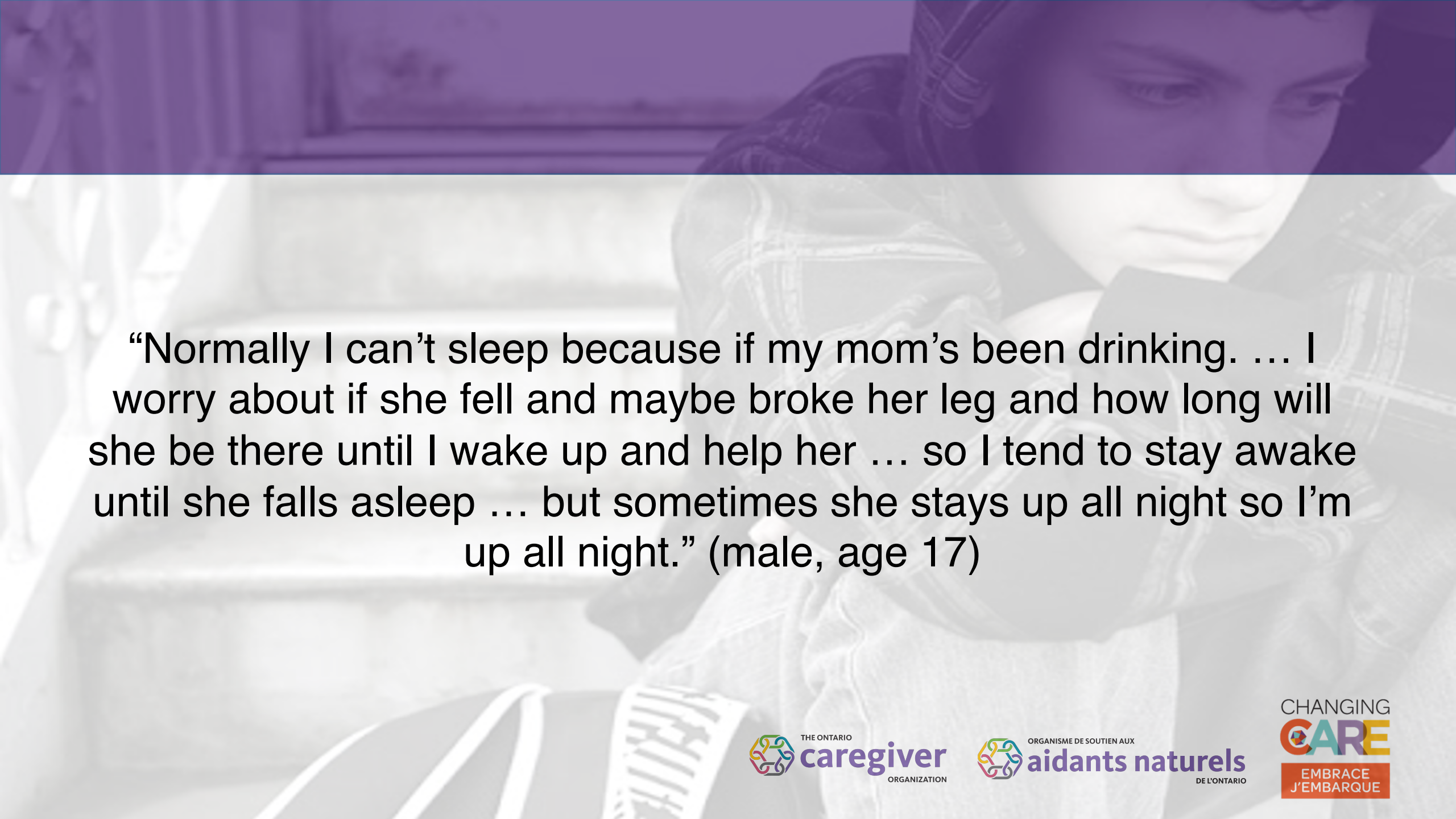


(Stamatopoulos, 2017)

The Young Caregiver Penalty

- Professional penalties: employment and education
 - Few young caregivers were able to take on part-time or casual work due to their added responsibilities at home and the on-call nature of their caregiving.
 - Lack of sleep, concentration difficulties, increased lateness, absences, and a lack of available time required for homework and studying
- Personal penalties: familial, social and emotional
 - Feelings of resentment and/or strain in the family unit
 - Most youth indicated they had very little “free time” to pursue hobbies or leisure activities, less still to spend with friends.
 - Feelings of distress, fear and anxiety about their responsibilities or the state of their care-recipient

(Stamatopoulos, 2017)

A young man with dark hair, wearing a plaid shirt, is looking down at a smartphone in his hands. The background is a blurred indoor setting. The image has a purple tint at the top and a white overlay for the text.

“Normally I can’t sleep because if my mom’s been drinking. ... I worry about if she fell and maybe broke her leg and how long will she be there until I wake up and help her ... so I tend to stay awake until she falls asleep ... but sometimes she stays up all night so I’m up all night.” (male, age 17)

Supporting Young Caregivers: Recognition

One of the greatest challenges that these youth face is the lack of recognition regarding the fact that youth can be in a caregiving role.

Young caregivers are often unaware of the position they are in for a variety of reasons, including their role being normalized.

As well, frontline workers, community agencies and government bodies often do not recognize these youth as caregivers because “it’s just not something you think happens”. However, these youth are everywhere!

How might a young caregiver talk about their role, without knowing it? Do you see this in your work?

(e.g. “I love my dad and someone needed to step up to help him, so I did. I didn’t realize this wasn’t; something that was normal “kid” behavior”. -Young Caregiver, 15 years old)

Supporting Young Caregivers: Recognition

If you suspect that a young person may be a caregiver, we urge you to explore that with them. Here are some “young caregiver” approved conversation starters:

- “I heard you say that you spent all weekend at the hospital with your sister, would you be okay with telling me more about that?”
- “As you were talking, a thought came to mind... some youth are “caregivers”, which means that they provide some sort of care for someone in their life. When I heard you say _____, it made me wonder if maybe you were too. What do you think?”
- “I often see/hear of you providing support for your partner. Do you often support them? If so, how?”

Supporting Young Caregivers: Emotional Support

Caregiving is often referred to as an “emotional rollercoaster” for so many different reasons, including (but not limited to):

- Unexpected changes in one’s health and ability to cope, causing worry and panic.
- The youth may feel they are missing out on opportunities (ex: hanging out with friends or going away to school).
- Resentment and anger when an episode occurs at an inappropriate time (ex: a concern over a parent experiencing a drug overdose at a High School graduation).

In learning to deal with this “emotional rollercoaster”, young caregivers have asked that the people in their lives **validate** their feelings and experiences.

Supporting Young Caregivers: Coping

Below are some suggestions that could help young caregivers cope:

- A lot of youth struggle to speak about their caregiving role, so it could be helpful to help them advocate for their needs, such as setting boundaries with family or getting accommodations in school.
- Create a plan for young caregivers to empower them to seek help and support:
 - Have a list of people or organizations who can help provide support when things get challenging (ex: who can you vent to ? Who can provide you with respite?)
 - What would be indicators that things are getting harder and that you might need more support?
 - How do you recognize a crisis situation? Is there a protocol in place for emergencies? Does the young caregiver know who to call?

What are some other coping mechanisms that could be helpful for young caregivers?

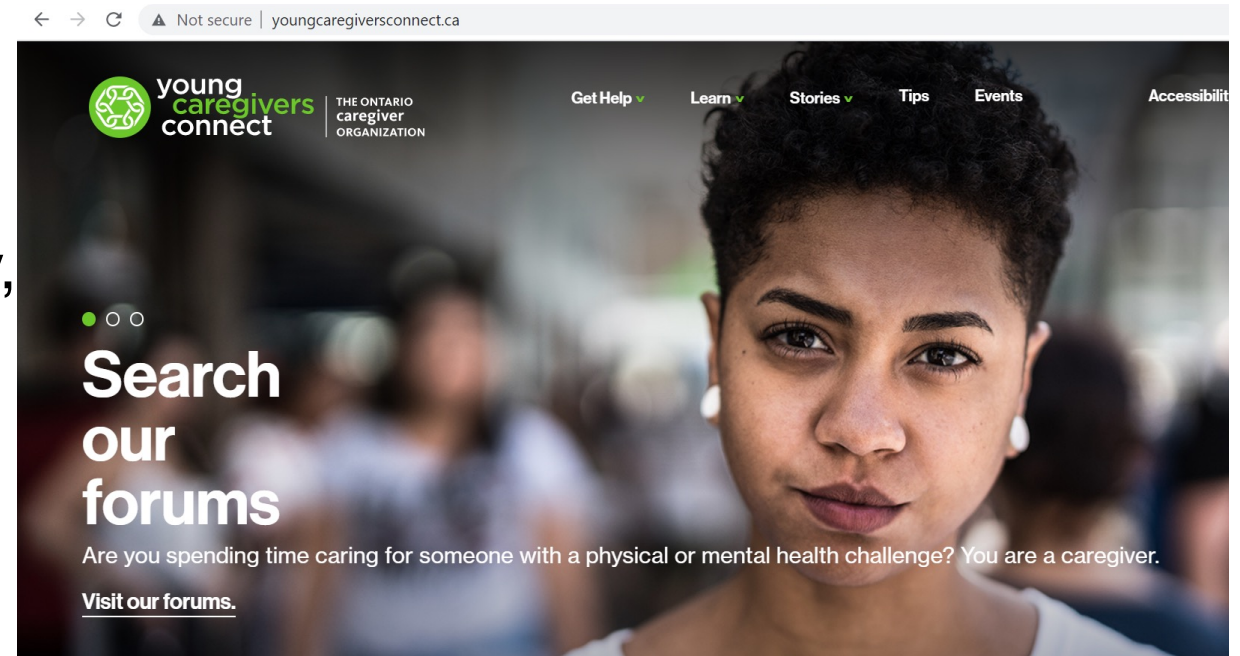
Supporting Young Caregivers: Self-Care

Below are some suggestions regarding what could be included to support young caregivers' self-care:

- Practicing Gratitude (e.g. identifying 1 thing you are grateful for related to caregiving)
- Creating self-care plans when young caregivers start to feel overwhelmed (e.g. When I feel anxious, I will draw, play guitar, etc.)
- A pledge of boundaries that they will not cross (e.g: I will not text answer my dad's texts while at school, unless it is an emergency)
- A list of numbers / agencies to turn to if they feel unsafe or overwhelmed

Some supports for young caregivers

- YoungCaregiversConnect.ca
 - Information developed for young caregivers, by young caregivers
 - Connect with other young caregivers on our online community, watch videos, etc.
- OCO Young Caregiver Support Group (Wednesday evenings)
- Ontario Caregiver Helpline (available 24/7)– 1-833-416-2273



In Conclusion...

**Never undervalue the impact that you
have as a caring and curious adult.**

Special thanks

Thank you to Micaela Harley; student, professional, advocate and young caregiver, for your work developing this important material.



Questions?

Kathleen Slemon

kathleens@ontariocaregiver.ca

437-335-2109

To learn more about The Ontario Caregiver Organization:

www.ontariocaregiver.ca

Youngcaregiversconnect.ca



References

Buck, H. & Harkness, K. (2014). Caregivers' contributions to heart failure self-care: A systematic review. *European Journal of Cardiovascular Nursing*, 14(1). DOI: 10.1177/1474515113518434

Stamatopoulos, V. (Forthcoming). Supporting or separate domains? Parentification and young carers in Canada. In L.M Hooper (Ed.), *Parentification: racial, ethnic, cultural, and contextual influences on culturally tailored assessment and treatment*. New York, NY: Springer-Science.

Stamatopoulos, V. (2018) The young carer penalty: Exploring the costs of caregiving among a sample of Canadian youth, *Child & Youth Services*, 39:2-3, 180-205, DOI: [10.1080/0145935X.2018.1491303](https://doi.org/10.1080/0145935X.2018.1491303)