

Caring for Young Caregivers

Dr. Andrea Breen & Michaella Miller

Presentation Outline

- Introductions
- What is a “Young Carer”/ “Young Adult Carer”?
- Young Carers on campus
- Supporting Young Carers

Dr. Andrea Breen

Associate Professor, Department of Family Relations and Applied Nutrition,
University of Guelph

“When I was in high school I was caring for my dad who has early onset Alzheimer's...When I think of all the things I have done for my dad, clean the house, do the laundry, cook meals, bathe and dress my dad, constantly check on him to make sure he had not wandered out of the house. I did all of these things in conjunction with school work and a part time job. I would say being a young caregiver has given me patience and understanding of others, but it has also left me with guilt and a sense of loss.”

“My grandmother had cancer and was fighting severe anxiety. I was up with her late at night... and staying with her until she fell asleep. It prevented me from being fully and properly rested for school or completing my work to the best of my ability. There were negative effects of having to care for her but it brought me closer to her”.

- Under age 29
- Provide unpaid care to relative or friend living with illness, disability, addiction, injury
- Tasks performed include personal, physical, household, health care, communication, emotional

**Estimated 1.8 million Canadians are young carers
THIS NUMBER IS INCREASING.**

- Majority support grandparents (40%) followed by parents (27%), Friends/neighbours (14%), Siblings/extended family (11%)
- 19% provide support for 3 or more people
- The amount of time young people aged 15-24 spend caring for others is similar to their middle aged counterparts

- “Care Act” (UK)
- “Children and Families Act” (England)
- “Federal Young Carer Bursary Program”
(Australia)

Benefits of young caregiving

- Practical life skills
- Sense of pride
- Heightened empathy and altruism
- Deeper connections with loved ones

Possible Negative Impacts of Being a Young Carer and a Student

Students who provide care are 4x more likely to drop out than their peers!

Physical effects

- Chronic stress
- Sleep problems
- Eating problems, substance use and self-harm
- Injuries from physical tasks (e.g. lifting loved one)

Psychological and Social Effects

- Chronic stress
- Anxiety, depression, isolation, anger
- Identity constraint
- Emotional exhaustion
- Difficulty maintaining friendships and romantic relationships

Educational effects

- Poor attendance
- Dropping out
- Incomplete or poor quality assignments
- Limited participation in academic and social activities

Unlike older caregivers, there are no financial benefits available to student caregivers

Young Carers are rarely given accommodations for school work

Student caregivers may work while attending school

Support for Specific Groups of Young Carers

- Young adult carers from racialized and cultural minority backgrounds
- Young male carers
- Young carers with learning difficulties

Putting a Face to the Statistics

Hi I'm Michaela



What is complex regional pain syndrome?

Complex regional pain syndrome (CRPS) is a chronic (lasting greater than six months) pain condition that most often affects one limb (arm, leg, hand, or foot) usually after an injury. CRPS is believed to be caused by damage to, or malfunction of, the peripheral and central nervous systems. The central nervous system is composed of the brain and spinal cord; the peripheral nervous system involves nerve signaling from the brain and spinal cord to the rest of the body. CRPS is characterized by prolonged or excessive pain and changes in skin color, temperature, and/or swelling in the affected area.



When

It Rains

It Pours

So here's what happened

What People See at University:

- Keeping up grades
- Coop job interviews
- Part time work

What People Didn't See:

- The acceleration of my sisters disease
- My other sister's major concussion and diagnosis of brain cysts and chronic migraines
- My father lost his job and his depression
- My mother travelling for work and her stress
- My toxic relationship

How it affected me

- Panic attacks
- Weight loss and disordered eating
- Lower than normal grades
- Missing classes
- Withdrawing from classes
- Social strain
- A loss of control



Who I am now

- A Graduate
- A Masters Student
- An Advocate
- A Visionary

Positive Impacts:

- Resilient
- Persistent
- Dedicated
- Physically and Mentally Strong

Negative Impacts:

- Scholarships
- Missed Opportunities
- Volunteering experience

The Future - A Call for Action

- Recognition of my role and its impact
- Supports
- Policy and Legislation



Discussion: How Can You...

1. Make it easier for students to disclose?
2. Provide opportunities for support?
3. Foster wellbeing approaches for students?

Take Home Message!

- **Ask**

“Do you provide support or care for a family member or loved one, either in or outside your home?” (Chadi & Stamatopoulos, 2017)

- **Advocate**

- campus inclusion policies

- raise awareness

- **Accommodate**

- **support academic accommodations!



STUDENTS WHO ARE CAREGIVERS

What Postsecondary Institutions Need
to Know

https://atrium.lib.uoguelph.ca/xmlui/bitstream/handle/10214/10511/BouleJ_StudentCaregivers.pdf?sequence=3&isAllowed=y

Resources and Readings

Action Canada Task Force (2013). Who cares about (young) carers? Raising awareness for an invisible population. (Report). <http://www.actioncanada.ca/project/cares-young-carers-raising-awareness-invisible-population/>

Boulé, J. D. (2017). *Students who are caregivers: What postsecondary institutions need to know*. University of Guelph.
(https://atrium.lib.uoguelph.ca/xmlui/bitstream/handle/10214/10511/BouleJ_StudentCaregivers.pdf?sequence=3&isAllowed=y)

24

Breen, A.V. (2016, April 5). *It's time to care for our (young) carers*. Retrieved from <http://vanierinstitute.ca/time-care-young-carers/>

Carers Trust (2015). *Supporting students with caring responsibilities: Ideas and practice for Universities to help student carers access and succeed in higher education {England}*.
https://professionals.carers.org/sites/default/files/supporting_student_carers_fe.pdf

Resources and Readings (Continued)

Chadi, N. & Stamatopoulos, V. (2017). Caring for young caregivers in Canada. *Canadian Medical Association Journal*, 189, 25-26.

Change Foundation (2017). *Programs and Services Supporting Ontario's Young Carers*. (Report). <https://www.changefoundation.ca/ontarios-young-carers/>

Charles, G., Stainton, T., & Marshall, S. (2012). *Young carers in Canada: The hidden costs and benefits of young caregiving*. Ottawa, ON: Vanier Institute of the Family.

Stamatopoulo, V. (2015) One million and counting: the hidden army of young carers in Canada, *Journal of Youth Studies*, 18, 6, 809-822, DOI: 10.1080/13676261.2014.992329

Young carers Project (2015). *Support Matters: A guide for young carers and their allies* [By us for us guide]. www.youngcarerproject.ca