



### **Students Who Care**

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In general, young adulthood is a time in a person’s life where there are endless possibilities and future opportunities for “success”—however that may be defined. Responsibilities like marriage, parenthood and careers are often delayed in order to seek out a higher education, like attending university or college. During this life stage, young adults develop new relationships and connections where they may travel, live independently for the first time and experience an overall exploration of their identity<sup>i</sup>.

A young carer though— a person between the ages of 15-29 providing unpaid care to a family member, friend, or partner living with an illness, disability, addiction, or injury— may not have the supports in place to help them through these changes while at the same time meeting their caregiving responsibilities<sup>ii</sup>. The reality is, being a caregiver is a stressful task; one that may become more difficult when there are additional pressures like school<sup>iii</sup>.

From the little research we do have on young carers, we know that those enrolled in university or college are four times more likely to drop out and experience an array of damaging physical, mental, emotional, social, financial and educational effects when they are lacking support<sup>iv</sup>. On the other hand though, when young carers are being supported, positive aspects begin to surface like a greater sense of empathy, compassion, resilience and self-efficacy. Relying on support networks also provide young carers with a sense of belonging, increased self-worth, and feeling of security<sup>v</sup>.

So why is it that I feel the need to write about young carers, and more importantly why should you care? First off, I used to be a young carer although I didn’t recognize this identity at the time. I provided emotional, physical, and financial support, while also attending to daily tasks like meal preparation,

transportation, and other everyday chores for another person without pay. But the pressures of trying to juggle the roles and responsibilities of being a caregiver, student, employee, volunteer, friend and partner often became overwhelming.

Whenever I left the house I felt stressed, guilty, and worried about leaving the person I was supporting. Staying focused during classes was an impossible task that typically led to skipped lectures, late assignments, and poorly written exams. I felt as though I couldn't share my experiences with anybody, because in all reality who would understand? Even when I tried to make time for myself or friends, I was never *really* there. So, it is because of my past that I wrote this article. I wanted to share my experiences and let other students in similar circumstances know they aren't alone.

As I was working on this project though, I became aware of other young carers on campus and learned their stories. Although they were eager to share their experiences with me and have the public understand what caregiving as a student is like, they each requested that their names be replaced with pseudonyms to maintain their own privacy, and that of their friends and family.

Here's what students who care would like for you to know:

### **Young carers have a hidden identity:**

Ellie F. is a one of the three young carers I had the pleasure of meeting. At the age of 21, Ellie is a promising university student with the world before her and endless opportunities. Between caring for her grandmother, working part-time, volunteering, building connections and applying to graduate school, Ellie is an extremely busy, motivated, and intelligent student. While Ellie is not the sole provider for her grandmother, the exhaustion, worry, stress and guilt she feels weighs just the same. When asked about her level of supports, Ellie cannot name any on campus and shares that she does not feel comfortable with discussing her caregiving role with her peers, the faculty or other support staff her university.

*I have a friend in a similar situation, she gets it. So I do all my projects with her... otherwise I don't go to anybody on campus for support.— Ellie F.*

Drs. Grant Charles, Tim Stainton and Sheila Marshall, of the University of British Columbia, are some of the few Canadian researchers exploring the topic of young carers. In the Vanier Institute of the Family Publication, *Young Carers in Canada: The Hidden Costs and Benefits of Young Caregiving*, the authors consider that young carers continue to remain hidden because of a fear of stigmatization, or disapproval from society of their caregiving role. Because of this, the term '*parentification*' may have negative impacts on young carers because it implies that the roles of the child and parent have been reversed, and that the parent-to-child support that is expected is no longer present, or considered "healthy"<sup>vi</sup>.

Jenn P. is an example of this. A 24-year-old student who has been providing care for her father for as long as she can remember, she recognizes that falling outside the norm during a vulnerable stage in life can leave a person with the fear of being judged:

*Yeah, like, I never actually wanted to tell anybody about what it is like at home because people would think it's weird. Like, "why are you taking care of your dad, shouldn't he be taking care of you?" and then I would have to explain his entire history with drug addiction and chronic pain, which again I feel like either I would be judged for... or he would. Which, just isn't fair. Neither of us can help the life we were born into. We can only move forward and this is the way that we have chosen to do that. —Jenn P.*

The invisibility young carers may be feeling is then worsened, since the term itself isn't really well known. Some students, including 23-year-old long-distance carer Blair S-M, question or not even recognize that they belong to this larger group identity.

*I have hesitations about even identifying as a young carer, because of my age especially, but also because I compare my caring tasks to others... trying to judge the worth of what they do. Like, is what I do enough to warrant calling myself a young carer? Would I even be a young carer, because I feel like things are good right now? It was hard before, it was really pressing. The care my partner does for their family is so different than what I do and I think just recognizing that and giving recognition to people who give care under any capacity is important. —Blair S-M.*

Dr. Vivian Stamatopoulos, an instructor at the University of Ontario Institute of Technology, recognizes that the term 'young carer' is unknown among the public as well; affecting the supports that young carers receive. In her article *Supporting Young Carers: A Qualitative Review of Young Carer Services in Canada (2015)*, Dr. Stamatopoulos reveals that England and Wales have roughly 432,250 young carers between the ages of 5-25, with approximately 1/14 youth receiving supports. Although Canada has shown much higher numbers of young carers, approximately 1.18 million young carers between the ages of 15-24, and far less supports exists as only 1/944 are receiving support<sup>vii</sup>.

### **Young carers are close with the person(s) they support:**

While chatting with other young carers on campus, I couldn't help but notice each student felt close to the person they were supporting. Even if this role left young carers feeling as though they had little time to attend classes; to spend additional time on assignments or studying for exams; to work more paid hours and/or; to visit friends or partners. Blair describes this issue well:

*I took a week off from school to be with my Grandma since she couldn't be alone. Grandma is really active and wants to go walking and do stuff... so I couldn't be writing papers when I want to spend time with her. — Blair S.M.*

Of all the carers I spoke to, not one ever felt regret towards the person they were supporting. In fact, young carers described very close bonds to the person they were providing support; bonds that other people may not necessarily understand.

*Without this deep connection with Nanny, I would never understand life. So that's why I say I would never take it back and it takes priority over my other relationships sometimes because it's not going to*

*be there forever...you know? I've said to my grandmother before I'm going to be a hot mess when you're gone...You are a part of who I am...it's a different relationship than everybody else. It's not just a grandmother-granddaughter relationship. She's my best friend. — Ellie F.*

### **Young carers are diverse:**

Although there were relatable experiences among the young carers I spoke to, not all were alike. Young carers differed by caregiving tasks, number of hours spent caregiving, their living conditions, the people they provided care to, and their reasons for providing care.

*My Grandma has Alzheimer's... It can be overwhelming when I'm away at school. I'm not able to just get in my car and see her. I can't just get her orange juice when she needs it. The caring from a distance part is difficult and the thing is I don't have a need to worry. My mom is there and she's the primary caregiver. When I come home and I am there, it's like a tag-team. —Blair S.M.*

*I've been supporting my dad since as long as I can remember... since the chronic pain started. Maybe like 4? My mom works nights to support us and all of my siblings have left home... I'm in school because of my parents. My Parents don't want to see me end up like them. They're counting on me to make something better of myself. —Jenn P.*

*I live at home with my family, they're loud with the Netflix. it's distracting. So I do all my studying at night time. Or my thing is like to go to bed at a reasonable time and get up at 6:00am and rock... 'Is Nanny fed? Is she happy?' I can go focus then on my studies... I need to know she's all set up and then I'm good ... I've had to stop working because of caregiving responsibilities, I can't sit at work. My mom always looks at me and says it's not my responsibility but I can't ...I would rather work more, but what are you going to do about it?—Ellie F.*

The diversity within just these three situations shows that the needs and experiences of young carers are complicated and may be hard to meet. Dr. Andrea Breen, Assistant Professor at the University of Guelph, recognizes that the needs of young carers are varied and that some may face overlapping challenges as a result of their community and limited social supports<sup>viii</sup>.

### **More inclusive supports on campus are needed:**

Having been a university student at three of Ontario's major universities while providing care, I realize that policies and supports are lacking in their inclusivity when compared to other countries like the UK. The gap of supports for young carers is all too clear for Ellie F:

*I get frustrated because people with learning disabilities get lots of help... The student supports should be there for everybody. I have friends who are single mothers and there's nothing for us caregivers. There's all these extra parts of our lives, and I show up to the library and there's nothing, not even a place to sit. I just get frustrated because I don't have many hours in the day, so I just wish I had a space to make those hours effective. I can't handle group projects for that reason. — Ellie F.*

The young carers I spoke with also discussed a need for deadline extensions and other support systems, which could be improved and instigated through a registration system that documents their caregiving status—rather than forcing students to discuss the personal contexts of their lives with professors or other faculty themselves. Other recommendations to improve supports included a young carer support group and online resources. While these young carers recognized other resources and supports like the *Young Carer Project* in Waterloo<sup>ix</sup> and the *Powerhouse Project* in the Niagara region<sup>x</sup>, they considered themselves too old or that the organizations were too far to access.

Carers Trust, a not-for profit organization located in the United Kingdom, supports caregivers of all ages. Through their research on young carers who are students, Carers Trust has developed solutions to inform policies and services at the postsecondary level to promote a young carers educational career<sup>xi</sup>. The frameworks make sense too, since they are based on the view that when a young carer has been acknowledged and offered the proper supports they are more likely to enroll (or stay enrolled), to achieve academic excellence and to find a career that relates to their academic interests. Knowing what we do about the potential benefits when young carers have supports in place, while recognizing the benefits that higher student enrollment rates and academic excellence have on a postsecondary institution's reputation, inclusive policies and supports seem like a compelling argument for structural change for postsecondary institutions across Canada.

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#### Notes

<sup>i</sup> Stassen Berger & Chuang, 2014

<sup>ii</sup> Day, 2015

<sup>iii</sup> Carers Trust, 2015

<sup>iv</sup> A. Breen, 2016; Action Canada Task Force, 2013; Carers Trust, 2015; Charles, Stainton, & Marhsall, 2012; Day, 2015; Stamatopoulos, 2015; Young Carers Project, 2015.

<sup>v</sup> A. Breen, 2016

<sup>vi</sup> Charles, Stainton, & Marshall, 2012

<sup>vii</sup> Stamatopoulos, 2015

<sup>viii</sup> A. Breen, 2016

<sup>ix</sup> [www.youngcarersproject.ca](http://www.youngcarersproject.ca).

<sup>x</sup> [www.powerhouseproject.ca](http://www.powerhouseproject.ca)

<sup>xi</sup> Carers Trust, 2015

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