

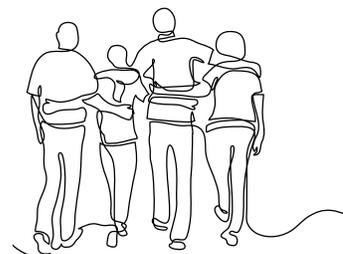


# YOUNG CARERS

**Young Carers<sup>1</sup> are a distinct group of caregivers, whose experience is equally important to understand. Our 2019 survey heard from 71 young carers.**

**Our findings include:**

- Among young carers (16 to 25<sup>2</sup>) there are an equal number of male and female caregivers.
- Notably, 49% of the young carers have been caregiving for more than a year with 15% providing care for the past 5 years.
- 51% of young carers mostly provide care to their extended family members – with 35% most likely caring for their grandparents. They are the largest caregiver group providing care to their siblings (14%) or a friend/neighbour/colleague (16%). 24% are likely caring for more than one person.
- 44% of young carers usually reside in the same house as the person they are caring for.
- Although 71% of young carers feel their role should be seen as important, 38% are more likely to feel that their role should not be given the same level of importance as other members of the healthcare team. While 22% do see themselves as equally important, only 11% see themselves as one of the most important members of the healthcare team.
- Interestingly, 62% of young carers prefer to approach friends and family first for information followed by 57% turning to the internet.
- 50% of young carers feel they did not have a choice in their role and feel less fulfilled and rewarded than other caregiver groups.
- 77% of young carers do not self-identify as caregivers. Even after hearing a definition of caregivers, 40% young carers do not consider themselves to be a caregiver but guess this is what they are, 23% still do not accept the role and a further 14% say they never thought about themselves as caregivers before.
- Young carers are not as ready to accept their role as a caregiver (21%) and are more likely to say that they did not consider it as such earlier but do agree now (40%). Young carers are the most likely to still feel that they are not caregivers (23%) compared to the other age cohorts.
- 44% of young carers were happy to step in and provide caregiving responsibilities. However, 29% were also worried about the challenges that came with the role.
- 10% of young carers take on the primary responsibility of expenses and managing finances.
- Young carers are less likely to feel that their absence would affect the care receiver compared to other caregivers – particularly the level of healthcare (56%), physical activity (50%), lifestyle (58%) or that they would move to a higher level of care (44%).



*More than anything, what stands out to me is around caring for my grandmother and how some of the most important lessons she taught me came out of being with her as she navigated the progression of her illness...Some have memories of baking cookies with their grandmothers or getting their hands dirty in the garden. Mine are a little more subdued, playing the piano to distract her from discomfort or late-night conversations when she couldn't sleep.*  
- Caregiver Advisory Panel Member

*When I first became a caregiver, I didn't really know I was a caregiver, being only 15 at the time, I just accepted it as part of my new family responsibilities. However, I was scared and worried about what the future would bring due to the nature of my Mom's condition. I wish I had been brought into more conversations and told what to expect, it really could have helped me understand and prepare myself.*  
- Caregiver Advisory Panel Member

<sup>1</sup> A note on terminology: In Canada, the term family caregiver is commonly used. However, when it comes to younger caregivers, the young carer term has been adopted from the UK. It creates an inconsistency.

<sup>2</sup> Young carers are those between the ages of 5 to 24 years of age. However, due to age of consent, data from this survey is only available for those between the ages of 16 and 25 years old.