



THE NEEDS OF CAREGIVERS WHO SUPPORT SOMEONE WITH A MENTAL HEALTH CHALLENGE

Caregivers who support a child, youth or adult with a mental health challenge say providing care comes at a cost to their own physical and mental health. The Ontario Caregiver Organization surveyed 213 caregivers in this role to better understand their experience and unique needs. Findings include:

Mental health caregivers are often looking after a child or a spouse. They are most likely to live with the care recipient, have been a caregiver for a number of years and spend many hours a week providing care.

- Many of these caregivers are looking after only one person (57%), although 23% are looking after two, and 19% more than two. This is often their child, whether they are under 18 (23%) or 18 and over (51%), with 30% looking after a spouse.
- Three in five are putting in at least 10 hours of care a week (59%), with one-fifth (22%) saying they put in 100 hours or more a week.

While many mental health caregivers want to help the person they care for, this is not an easy task. They often feel unappreciated and resentful. Many admit they are under a great deal of stress and are not coping well with the situation. They feel other areas of their lives are negatively impacted and wish they had more support from family, friends, the community and society in general.

- Three in five (60%) say they were happy to step in and provide care and that their caregiving duties have a positive impact on their relationship with the care receiver (59%). However, 13% wanted to help but felt intimidated and 12% did not want to help at all. In addition, half (54%) often feel resentful.
- Mental health caregivers feel their work is not recognized outside their relationship, with 95% agreeing society does not understand the amount of time and effort involved, with 69% wishing they received greater empathy and respect from healthcare providers.
- When asked how they are coping emotionally, 57% say they are not coping well. As well, 47% say they are not coping well physically. They are anxious or worried (87%), overwhelmed (85%), frustrated, feel helpless and trapped (82%), and are getting disturbed sleep (80%).
- These caregivers say caregiving also has a negative impact on their own physical and mental health (each 85%), availability of leisure time (80%), and other relationships within their family (76%). Over half (55%) say being a caregiver has had a negative impact on their career growth.



Some of our stress comes from the fact that we don't see our loved one getting better. We know that they're not getting what they need. It always goes back to this. If they could be better, we can be better.

- Caregiver

My experience didn't just happen to my husband. It happened to me, it happened to us as a couple, to our family, his children and grandchildren. It affects everybody and you don't realize that at first.

- Caregiver

Mental health caregivers believe the healthcare system is not set up in a way to help them. Instead, they are often faced with a lack of support or information and face many barriers preventing them from providing the best possible care. They wish they could receive more support on several fronts, including a centralized and easily accessed place for information and advice, more support in the community and faster access to care.

- Half of mental health caregivers say they were left without the support they need. Specifically, as it relates to providing emotional support/counselling to the care receiver (53%), getting emotional support/counselling for themselves (56%), details about the illness they are dealing with (53%), and how to access caregiving support (47%).
- Mental health caregivers feel there are many barriers standing between them and the support they need to provide the best care. The barriers most often experienced are the cost of external or additional help (64%), the inability to find a professional, institution or community support to care for mental illness (51%), and a lack of information on how or where to get support (47%).
- Many also feel the healthcare system is not set up in a way that helps them, with almost all (95%) wishing there was one place they could go for advice, and only 14% agreeing the healthcare system is set up in a way that easily allows them to find proper support.
- Nine in ten (91%) wish there was more support from the community. This community support could come in many forms, with 90% wishing police and first responders were better trained on how to deal with people who have mental health challenges.
- Wait times are also a challenge with 91% saying they prevent their care recipient from getting the treatments they need when they need them.
- 83% agree it is difficult to understand how to get mental health support when transitioning from a child to an adult. Most also wish their child could get more support from their peer group (80%) and from the school system (63%).



The silos between healthcare and community and social services, those silos and how you bring people together is really, really, challenging... It's not just about caring for the person who has the highest needs. Sometimes the caregiver has a significant amount of need.
- Caregiver

We have to look far more seriously at the issue of how to assist those caregivers who do stay home, give up a job, don't contribute to CPP or EI while they're at home. And on top of that, when they retire, they will not have made contributions for those years that they were not in the workforce.
- Caregiver

Caregivers often find it necessary to fund the services and support of the person they care for themselves and many have experienced financial hardships because of it.

- Almost all (93%) wish there was more financial support from the government and 83% cannot always afford the treatments required. Four-fifths (81%) use their personal finances to pay for expenses and less than one-quarter have received financial help from government agencies (24%) or family/friends (20%).
- Two-thirds (66%) have experienced financial hardship or shortfalls in the past year due to caregiving and have had to cut back on spending to pay for caregiving expenditures (66%).

The Ontario Caregiver Organization surveyed mental health caregivers as part of The Ontario Caregiver Organization's partnership with The Change Foundation on the Spotlight on Ontario's Caregivers 2019 report. Two hundred and thirteen mental health caregivers participated. A random probability sample of this size would provide results that were accurate to within +/-6.7 percentage points, 19 times out of 20.