



THE CAREGIVER WISHLIST

Caring for the Mental Health
of Ontario Caregivers



THE ONTARIO

caregiver

ORGANIZATION

CARING FOR THE MENTAL HEALTH OF CAREGIVERS WISHLIST

SUMMARY OF FINDINGS

The Ontario Caregiver Organization surveyed and engaged with more than 1,000 caregivers to better understand the mental health impacts of caregiving and the factors that contribute to caregiver distress, anxiety and depression. The result is a three-part Caregiver Wishlist that reveals the key areas of need that caregivers believe, if addressed, can improve their own mental health.

CAREGIVER WISHLIST SERIES

Wishlist Part 1: Caring for the mental health of Ontario caregivers

Wishlist Part 2: Caring for the mental health of caregivers who support a child or youth with mental health challenges

Wishlist Part 3: Caring for the mental health of caregivers who support an adult with mental health challenges

There are 3.3 million Caregivers in Ontario. One in four experience distress, anger or depression.

- HQO 2018 Measuring Up Report

The Ontario Caregiver Organization exists to support Ontario's 3.3 million caregivers; ordinary people who provide physical and/or emotional support to a family member, partner, friend or neighbour. Our Wishlist series is meant to encourage caregivers to reach out for supports early in their caregiving journey, as well as create a dialogue about the mental health of caregivers among caregivers, health care professionals, service providers, policy makers and the general public. The Ontario Caregiver Organization will continue to engage caregivers in this conversation and will use the wishlist series to guide the work.



Emotional Effects of Caregiving

Caregivers told us that caring for someone can be an overwhelming responsibility. They struggle with guilt; afraid they aren't doing enough to support the person they care for and they grieve the loss of what might have been. They don't know how to be a caregiver or what's expected of them, and experience extreme isolation and loneliness as friends and family drift away. The emotional effects of caregiving begin early in their journey.

As caregivers begin to interact with the health care system and social services, these feelings are compounded. Caregivers feel left out of the care planning and often feel dismissed and sometimes judged or blamed for the condition of the person they care for. They are frustrated by how difficult it is to navigate the health care system and social services.

Financial Impacts of Caregiving

In addition to the emotional impacts, there are financial impacts of being a caregiver. Mental health services are seen as prohibitively expensive. Some are forced to use their line of credit to pay for care, others are unable to afford the care needed. Caregivers are reluctant to invest additional money in their own mental health.

Adding to the financial strain, many caregivers have to give up their job or they have lost their job as a result of their caregiving responsibilities. Those who still work find it difficult to balance their job and caregiving.

“Being totally alone and feeling like you’re alone is overwhelming. I think it’s the first step to having mental health issues around this.”

- 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

WISHLIST PART 1:

CARING FOR THE MENTAL HEALTH OF ONTARIO CAREGIVERS

Caregivers who provide physical and emotional support to a family member, partner, friend or neighbor wish for:

1. Greater Empathy and Respect

Caregivers don't want to be treated as a nuisance. They want to be a partner and contribute to the decision making and care planning. Caregivers want health and service providers to have more training on how to engage with families and caregivers.

2. Help Navigating the Health Care System

Caregivers experience a great deal of frustration navigating a complicated health care system. This part of their role takes a significant amount of time; time that caregivers don't have as they work to balance their caregiving responsibilities with their own family and work. Caregivers want help so that navigation is easier and more efficient.

3. Easier Access to Information and Resources

Caregivers often receive too much information upfront and find it hard to understand because they are already overwhelmed and stressed. Other times, they have difficulty finding the information they need, specifically when it comes to available resources. Caregivers want the right information at the right time.

“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



4. Greater Understanding of the Caregiving Role - Caregiver Training

Caregivers start their journey scared and they are unsure of what their role is, how to do it or what to expect. They need support, just as much as the patient does. Caregivers want role clarity and better understanding of how to be a caregiver.

5. More Hands-On Support for Caregivers

Caregivers need time to care for themselves but many don't take the breaks they need. They find it hard to admit they need help or they can't find the support they need. Often times, the respite they receive isn't enough to get things done and to also re-charge. They also wish they had someone to talk to - access to counselling or a caregiver support group.

6. General Awareness and Peer Support

Caregivers need support, not just from the health care system but they want greater support from employers, schools and their community at large.

“My experience didn't just happen to my husband. It happened to him, 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

WISHLIST PART 2:

CARING FOR THE MENTAL HEALTH OF CAREGIVERS WHO SUPPORT A CHILD OR YOUTH WITH MENTAL HEALTH CHALLENGES

Caregivers who support a child or youth with mental health challenges wish for:

1. Greater Empathy and Respect

Caregivers supporting a child or youth with mental health challenges want open and respectful dialogue with health care providers; free of bias and judgement. Caregivers want to be recognized and be part of the team and decision-making.

2. Help Navigating the Mental Health System

Caregivers don't know where to get the help they need. They struggle to navigate a complex mental health system. They want a health care system that is holistic, where doctors and service providers treat the person's health in its entirety, including their mental health while also helping to coordinate care.

3. Easier Access to Information and Resources

Caregivers said they have reading fatigue. They want access to information in a variety of ways, including phone calls, emails, in-person meetings, videos and written materials. Caregivers also want health care providers to have easier access to information about the person they care for. Caregivers say digital health could greatly improve their own journey and alleviate the stress of having to tell and re-tell

"I just didn't know where to go. They would give us a bunch of business cards. It's very confusing. They don't even know where to send you so you end up having this deck of cards where you don't even know where to turn."

- Caregiver

their story. Caregivers want health care providers to be more knowledgeable about the resources available.

4. Timely Access to Child and Youth Mental Health Services

Caregivers want the person they care for to have timely access to care. Wait lists are long, often times they wait months to see a mental health specialist. They want to be more proactive in order to avoid a crisis and a trip to the emergency room.

5. Health Care Provider Education

Caregivers want health care providers to have more education on how to support and work with caregivers. Caregivers spend a significant amount of time preparing the child or youth to receive support. Caregivers need more notice of their appointment date so they can ensure the child or youth is agreeable to receive the care. Conversely, caregivers want health care providers to know that when appointments are cancelled at the last minute, it has a significant effect on the person they care for and the caregiver who has to start the process all over again.

6. Affordable Mental Health Care

Cost of care can be expensive and much of the expense isn't covered by OHIP or workplace benefit programs. The financial burden associated with caring for a child or youth with mental health challenges contributes to feelings of anxiety and despair.

7. Greater Family Engagement

Caregivers say the mental health system is too “patient-centric” and needs to focus more on the family. Privacy and consent laws create a barrier for caregivers to provide support. Caregivers believe mental health providers rely on privacy and consent laws to shut families out of a person’s care. They want health care providers to engage with them so they can have a greater understanding of the situation.



“Families are a piece of the puzzle with everyone else on the team. We have to be respected as incredibly knowledgeable people that will help with access to care and with consent, capacity, and privacy issues.”

- Caregiver

8. Equitable Access to Mental Health Services

Caregivers living in rural areas are challenged to find the expertise that they need. Some consider moving to an area where they have greater access to specialists and services. Caregivers wish for a system in which people could access quality care regardless of where they live.

9. Caregiver Support

Mental health is an issue that affects the entire family. Caregivers want help caring for their own wellness. They want self-care training, counselling, respite and peer support. Caregivers also need on demand advice. Crisis doesn't happen from 9 - 5, they want someone to call when they need guidance that doesn't require police or a trip to the emergency room.

10. Peer Support for the Child or Youth

Caregivers recognize the benefits of peer-to-peer support for the child or youth. They see it as helping to remove the isolation factor, breaking down stigma, helping with coping skills and building resiliency, self-esteem and a greater connection to resources in the community.

11. Greater Support from Employers

Caregivers find it hard to support the needs of the child or youth and still manage the responsibilities of a job. Many are forced to leave their work or are fired. Caregivers want employers to have more compassion and to support them so they can continue to stay in the workforce.

12. Greater Support from Schools

Caregivers see the educational system as having an important role in supporting the mental health of children and youth. Caregivers would like to see school staff trained on warning signs of suicide. They would also like to see the school's health curriculum to include 'how to keep our minds healthy' and



"I feel like caregiving is like playing golf in the dark".

- Caregiver

"I think for me and my sister who I care for, our education has been impacted. I've been in school for six years, I'll be doing one more year before I graduate but it also doesn't allow me to become what I wanted in my life because I was busy giving care."

- Caregiver

cognitive behavioural therapy. They would also like to see greater communication between schools and parents to help with early identification of issues.

13. Police Training

Caregivers want police to have more training on how to engage with children and youth with mental health challenges. Caregivers feel that their approach often causes more harm to the child or youth.

14. An Easier Transition to Adult Mental Health Services

Caregivers recognize a dangerous gap in the mental health system: at the age of 17, patients are suddenly dropped and face long wait times to re-enter the system as adults. Also, during this time, parents are restricted in their involvement due to privacy and consent laws. Caregivers want the system to do more to care for people with mental health challenges between the ages of 16 and 30.

15. Public Awareness and Peer Support for the Caregiver

Caregivers want greater public awareness of their role and their needs. They want community support which can come in the form of meals and visits from friends. Caregivers say the best help comes from those who are going through the same thing, as they are the best at providing empathy and education about resources and skills. Peer support groups give caregivers the space to acknowledge their stress and feel less alone. Caregivers wish for a day when they can speak more openly about mental health and when mental health issues would be better understood.

“When we first started this journey I did the long search to see what was out there and I actually came upon Parents With Children’s Mental Health and their support groups and they have a peer to peer family support and I became actively involved in that. And that became my lifeline.”

- Caregiver



WISHLIST PART 3:

CARING FOR THE MENTAL HEALTH OF CAREGIVERS WHO SUPPORT AN ADULT WITH MENTAL HEALTH CHALLENGES

1. Greater Empathy and Respect

Similar to caregivers who support a child or youth with mental health challenges, caregivers supporting an adult feel health care providers judge and blame them for the situation. They want health care and service providers to be trained on how to engage with caregivers and have a greater understanding of the impact the situation is having on the caregiver. Caregivers want to be asked about what they need.

“I think there is also a problem with health care providers and lack of empathy. A lot of that comes from providers being burnt out.”

- Caregiver

2. Help Navigating Multiple Systems

Caregivers want help navigating the mental health care system. They don't know where to get the help needed. Caregivers recognize that when they do finally find the right number to call, there is a wait list. Caregivers also want help accessing a range of services outside of health care including housing and job training for the person they care for. They want such a service to understand the local resources in the caregiver's community. Some services aren't obvious so it really requires someone who lives in the community.

“I want one place to go. One number to call to get into a system where I'm trained, introduced to caregiver meetings, and where you learn all sorts of things. I wish there was a thing as an Alzheimer's society for mental health.”

- Caregiver



3. Easier Access to Information and Resources

Caregivers want easy access to information about resources available for the person they care for but also for themselves.

4. Timely Access to Services

Caregivers see the greatest impact on alleviating the burden for caregivers as being more timely access to mental health services, not just psychiatrists but the range of services that an individual might need to improve their mental health. This could include counseling, peer support, housing information, fair wage, job training. Caregivers want more day programs that the person they care for can participate in – programs that would reinforce lifestyle skills such as budgeting, socializing and eating well.

5. Caregiver Training

Caregivers want an education on how to be a caregiver to someone with mental health challenges. How to manage challenging situations and how to care for their own mental health.

6. Family Engagement

Caregivers want their role to be recognized by health care and service providers. They want to be part of the decision-making process.

8. Caregiver Supports

Caregivers recognize the need to care for themselves. They see counselling, peer support groups and respite as key ways to take care of their own mental health needs.

“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

“Every person has different needs. It’s not a cookie cutter. I would like to work with someone to help me with developing a care plan. I’m part of the care plan.”

- Caregiver

WISHLIST SUMMARY



CAREGIVERS CONCERNED ABOUT THEIR MENTAL HEALTH WISH FOR:

1. Greater Empathy and Respect from Health Care and Service Providers
2. Help Navigating a Complicated Health Care System
3. Easier Access to Information
4. Greater Understanding of the Caregiving Role – Caregiver and Health Care Provider Training
5. More Hands-on Support for Caregivers
6. General Awareness and Peer Support



CAREGIVERS WHO SUPPORT A CHILD OR YOUTH WITH MENTAL HEALTH CHALLENGES WISH FOR:

1. Greater Empathy and Respect
2. Help Navigating the Mental Health System
3. Easier Access to Information and Resources
4. Timely Access to Child and Youth Mental Health Services
5. Health Care Provider Education
6. Affordable Mental Health Care
7. Greater Family Engagement
8. Equitable Access to Mental Health Services
9. Caregiver Support
10. Peer Support for the Child or Youth
11. Greater Support from Employers
12. Greater Support from Schools
13. Police Training
14. An Easier Transition to Adult Mental Health Services
15. Public Awareness and Peer Support for the Caregiver

A photograph of a person wearing a pink top, standing outdoors with their back to the camera. They are looking towards a path that leads into a lush, green park-like area with many trees. The lighting is bright and natural, suggesting a sunny day. The person's hands are clasped behind their back.

CAREGIVERS WHO SUPPORT AN ADULT WITH MENTAL HEALTH CHALLENGES WISH FOR:

1. Greater Empathy and Respect
2. Help Navigating Multiple Systems
3. Easier Access to Information and Resources
4. Timely Access to Services
5. Caregiver Training
6. Greater Family Engagement
7. More Caregiver Supports





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