

Preparing to care:

Perspectives of
Ontarians who expect
to be a caregiver in
the next 5 years



The Ontario Caregiver Organization (OCO) exists to improve the lives of Ontario's estimated 4 million caregivers; ordinary people who provide physical and/or emotional support to a family member, partner, friend, or neighbour. OCO provides caregivers with one point of access to information, services, and supports that empower and help enable caregivers to be successful in their role. Where gaps exist in caregiver programs and services, OCO partners with caregivers, health care providers, and other organizations to find new and innovative ways to bridge those gaps so all caregivers, regardless of age, condition, or geographic location have access to the help they need.

At the Ontario Caregiver Organization (OCO) our purpose is to improve the lives of Ontario's caregivers. This includes planning for the growing number of caregivers in Ontario and the supports future caregivers will need. Recently, we surveyed Ontarians who expect to face caregiving demands in the next five years.

These insights help us to understand the concerns and complexities prospective caregivers are facing and what may be needed from an organization like OCO to support them. The results can help all of us to understand the steep growth in the number of caregivers that is coming as well as the barriers they are already expecting to face in that role. We believe these insights can inform important system planning, resourcing, and interpersonal conversations about the role of caregivers in the coming years, and we hope you find this information useful as well.

Over the next 5 years, the number of Ontarians providing physical or emotional support to a family member, partner, friend, or neighbour could increase by more than 50% - from 4 to 6.5 million people. However, another 2.7 million Ontarians are expecting to face caregiving demands but have already decided they can't or won't do it. The reasons are varied, with most saying they don't feel confident in their ability to handle the responsibility physically, mentally, or financially, or they believe the healthcare system will provide the care that is needed.

These new insights add another dimension of complexity to the capacity issues we are facing in our healthcare and social systems today, and are vital for us to explore and plan for, given the significant reliance society has on family caregivers.

This report reflects what prospective caregivers, those who expect to take on caregiving responsibilities in the next five years (e.g. based on age-related needs), are, or are not, thinking about. While this group feels it is important to be planning to provide care, very few are taking steps to prepare to do so.

The insights in this report can help inform planning across health and social care settings, as well as for individual prospective caregivers, so they may be better prepared for the future demands caregiving may place on them.



THE NEED TO RECOGNIZE AND SUPPORT CAREGIVERS IS GREATER THAN EVER



It is widely accepted by our system partners that our province is poised to face an unprecedented demand for access to primary, hospital, home, and long term care, as well as community and social services. The expected population surge, particularly among those over the age of 65, along with the increase in people living with chronic illness, will place extraordinary pressure on family caregivers who provide 75% of the care in the healthcare system.

As a society, we often speak of “aging at home.” This is what most of us want for ourselves and others. However, achieving this goal will require support beyond what healthcare and social systems alone can provide. The demand for caregivers will continue to grow, and the insights provided by current and prospective caregivers indicate that their capacity to provide care may be limited due to factors such as financial pressures and burnout. If aging at home is truly a priority, supporting caregivers and prospective caregivers must be one as well.



Whether you are a care provider, employer, or educator, we all have a role to play in supporting family caregivers throughout their journey, including identifying current and prospective caregivers early so that plans and support can be put in place.

THE CAREGIVING EXPERIENCE

OCO's [2024 Spotlight Report](#) once again reveals that caregivers are taking on more responsibilities, the financial impact of providing care continues to grow, and more caregivers are feeling the negative impact on their physical and mental health. Feelings of caregiver burnout and depression increased again in 2024.

While most caregivers in Ontario are caring for just one person, almost one-in-five spread their caregiving efforts across two or more people.

Caregivers in the role today say they were not prepared to become a caregiver.



36% say they were not prepared for the impact it would have on their ability to work



36% say they were not prepared for the impact caregiving would have on their financial situation



38% say they were not prepared for the amount of time it would take to provide the care required



44% say they were not prepared for the impact it would have on their life



PERCEPTIONS OF CAREGIVING



We asked prospective caregivers what they expect the role to entail and whether they feel prepared.



70% say they feel somewhat informed as to what will be expected of them



36% don't feel confident they can cover the costs associated with caregiving

Dealing with a care recipient's declining health and making sure their needs are met, balancing caregiving and other family responsibilities and work, and managing one's own emotions are viewed as the most stressful aspects of caregiving for prospective caregivers.



94% of prospective caregivers say it is important to be prepared to handle caregiving duties, but more than half have not started to make plans.

How caregiving will impact:	% of prospective caregivers who say they understand the impact of caregiving
Ability to work	82%
Health and well-being	80%
Personal life	79%
Finances	78%
Relationship with family members	68%

Caregiver's confidence in the ability to:	% of prospective caregivers who say they do not feel confident they can manage these aspects of caregiving
Spend the necessary time on caregiving	28%
Handle caregiving responsibilities overall	28%
Manage both caregiving and work responsibilities	31%
Manage caregiving with other responsibilities	31%
Cover the costs associated with caregiving	36%

What prospective caregivers believe will cause stress	% of prospective caregivers who say this aspect of caregiving will be stressful
Dealing with care recipient's declining health	80%
Overall management of caregiver responsibilities	72%
Making sure care recipient's needs are met	72%
Finding services for care recipient	72%
Balancing caregiving and other family responsibilities	71%
Coordinating care and other activities for care recipient	71%
Managing own emotions	70%
Making decisions for care recipient	68%
Paying for care recipient's needs	68%
Managing family conflict about caregiving	67%
Managing legal affairs	67%
Balancing care and work	65%
Changing relationship with care recipient	63%

PREPARING FOR THE ROLE

Most of today’s caregivers are supporting someone who has gradually needed more help. Others came into the role suddenly, when the care recipient had an accident or experienced the sudden onset of an illness or condition.



76% of prospective caregivers say they expect the role to be difficult



1/2 of prospective caregivers say they have not started to plan for the financial cost of caregiving

How difficult do you think caregiving will be?	% of prospective caregivers who feel these aspects will be difficult
Mentally/Emotionally	76%
Physically	68%
Overall	76%

Extent of caregiving planning	% of prospective caregivers who say they have not started to plan for this aspect of caregiving
Care recipient’s housing needs	47%
Impact on job	48%
Financial cost	50%
Accessing care	53%
Time needed to provide care	53%
Impact on family life	54%
How workload will be divided	53%
How caregiving duties will impact personal life (time with friends/hobbies)	56%
Impact on health and well-being	59%
Saving money to ensure financial situation will not be impacted	54%



1 in 2 prospective caregivers have not started conversations about care needs, often because they feel the topic will be uncomfortable both for the recipient and themselves.

BALANCING WORK AND CAREGIVING

Prospective caregivers are expecting their employers to understand their caregiving role and to support them in managing it.



Experience in the Workplace	Prospective Caregivers' Expectation
Employer will understand my role as a caregiver and what I'm doing to manage it	71%
Employer will be flexible in terms of hours worked or ability to work from home to support ability to manage caregiving duties	62%
I will be able to speak about my caregiving role in the workplace	46%
Colleagues will be understanding towards my role as caregiver	73%

These numbers are higher than the responses of current caregivers, meaning employers should anticipate that employee expectations will increase around the support they expect their employer to provide.

FINANCIAL IMPACT

Almost 3 in 5 caregivers today are covering caregiving expenses such as costs for supplies, food, and/or professional help with their own money. On average, these out-of-pocket expenses are \$640 per month. A small portion (5%) are paying in excess of \$2,000 a month.



Only 1 in 4 prospective caregivers say they would be able to pay \$500 per month, and while 75% have thought of the financial impact, only 39% have done any planning around it.

How prospective caregivers will cover costs of caregiving	% of prospective caregivers who will use this strategy to cover caregiving costs
Ask other family members to help pay for bills	36%
Cut back on spending	35%
Withdraw from savings or investments	32%
Get a loan, mortgage, or line of credit	17%
Cut back on caregiving expenses	10%
Do not expect expenses to be more than I can handle	12%
Don't know	12%



Fewer prospective caregivers are willing to go into debt to cover caregiving costs, compared to current caregivers, yet less than half have started to plan for the financial impact.

CONCLUSION

As health and social care systems plan for the increasing capacity demands as the population ages, it needs to be understood that family caregivers are not prepared to bridge the gap. Seventy-five per cent of current caregivers feel so burned out they worry about whether they will be able to continue in the role. What's also concerning is there are an estimated 2.7 million Ontarians who will face caregiver demands in the next 5 years, but say they won't take on the responsibility because of a lack of confidence in being able to do so, the inability to cover the financial cost, or an expectation that health and social services will provide all of the care required.

OCO sees a new opportunity to provide prospective caregivers with information and planning tools that enable them to feel confident, for when they do find themselves in the caregiving role. By supporting Ontarians in the planning process, OCO hopes to reach people long before they are taking on caregiving responsibilities or their health and wellness is compromised. OCO will also continue to work with healthcare leaders, educators, and system partners in the adoption of caregiver-friendly practices that have shown to make a difference in the lives of caregivers.

As we work together to plan for the future of health and social care, it is vital that we consider the supports caregivers will need in their role in our families, communities, and care systems. We look forward to working with our system partners to develop solutions that will meet the needs of current and prospective caregivers in Ontario.



If you or your organization works with family caregivers, please reach out to learn more about what you can do to support them throughout their journey.

METHODOLOGY

An online survey was conducted among 2,220 Ontario residents, 16 years of age or older. Of these, 800 were self-reported caregivers, 314 expect to be caregivers in the next 5 years and 1,106 either felt it was unlikely that they would be in the position to take on this role, or were unwilling to do so.

Caregiving was defined as: Caring for someone who needed support due to physical or developmental disability, mental health condition, long-term illness, degenerative disease, an aging related condition or through long-term recovery from accident or surgery, or palliative care.

By this we mean providing help or care, usually without pay, to a family member, friend, neighbour or anyone else. This help may be personal and can include certain tasks such as helping with housework, assisting with meals and washroom needs, help with outdoor tasks, or anything else. It may also include providing physical support, assisting in certain healthcare related tasks such as monitoring medication, coordinating for or attending doctor's appointments or conducting basic medical procedures. This care can also be social or emotional support such that you are providing support or company to the person to enable them to be more socially included, driving them, shopping with or for them, or anything else.



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