THE ONTARIO CAREGIVER ORGANIZATION

SPOTLIGHT REPORT

THE IMPACT OF COVID-19 ON CAREGIVERS: YEAR TWO

NOVEMBER 2021

About the Ontario Caregiver Organization

The Ontario Caregiver Organization (OCO) exists to support Ontario's estimated 3.3 million caregivers; ordinary people who provide physical and/or emotional support to a family member, partner, friend, or neighbour. The OCO's mission is to improve the lives of caregivers by providing 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, the OCO partners with caregivers, healthcare 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. Established in 2018, the OCO is a not-for-profit entity funded by the Government of Ontario.

Acknowledgements

We greatly appreciate the time and openness of the 801 caregivers from across Ontario who participated in this survey and would like to extend a special thank you to those who agreed to share their experience with us, so the OCO can go beyond sharing numbers and give an authentic voice, via interview, to caregivers who are struggling to cope. We would also like to acknowledge Pollara Strategic Insights, who conducted the survey and prepared the background report on which this report is based. Their expertise and insights have been invaluable. We want to also take this opportunity to thank the caregivers who are part of our online caregiver advisory panel, and many working groups which give us an opportunity to generate ideas, collaborate on projects and apply their insights to everything we do.

TABLE OF CONTENTS

MESSAGE FROM THE CHAIR AND CEO

Dear Friends and Colleagues,

As caregivers ourselves and hearing from thousands of caregivers across the province, it is clear the past 18 months have been some of the most challenging. If there is anything positive to come from a pandemic, it is the expanded understanding of what caregivers do and why they are essential partners in care.

We often talk about the contribution caregivers make to the person they care for, but their contribution to Ontario's health care system cannot be ignored. Caregivers care for patients before and after a range of treatments and on an ongoing basis for those with chronic or long-term conditions. Caregivers hold important knowledge about medical history and enable people to age in their home, which is where they want to be. They are often the bridge between the family member or friend and healthcare providers, and they play a vital role at all stages of treatment, mitigating risk and supporting the best patient outcomes. Based on the hours they invest, and even just using minimum wage, we cannot ignore that their contributions are estimated at $28.5 billion dollars per year.

We also cannot ignore that as we approach the two-year mark of Covid-19, most caregivers are now dealing with their own challenges, in particular their mental health. This report looks at the impact of the pandemic on caregivers now, compared to the year prior, and the findings while not surprising, are alarming. At this point in the pandemic, 58% of Ontario's 3.3 million caregivers say they feel burnt out, underscoring the personal impact of caregiving.

The pandemic has made the role of the family caregiver harder than it has ever been before. More caregivers are investing 10 or more hours a week providing care. More caregivers say they feel exhausted, overwhelmed, worried, and trapped. Half say their mental health is worse than last year. The majority who work say they struggle to balance their job and caregiving responsibilities. The financial impact

is also greater than previous years and a third have thought about quitting their job to be more available to the care recipient. Outside of the day-to-day responsibilities, caregivers worry about the future of health care, specifically the shortage of personal support workers and nurses. Part of what has made their role harder is that caregivers say they are providing the kind of care typically provided by these professionals.

This year, the Spotlight Report is expanded to include commentary from caregivers. While the data shows the reality of the caregiving role clearly, hearing the authentic caregiver voice drives home the extent of the impact. It is our hope that this report will inspire all of us to consider the needs of caregivers, not just in the context of being successful in their caregiving role, but as people who are struggling to cope. We encourage healthcare leaders, front line care providers, employers, managers, family members and friends to think about what you can do to help a caregiver. At the end of this report, we have provided practical ideas that can make a difference.

Sincerely,

David Mosher
Board Chair, Ontario Caregiver Organization

Amy Coupal
CEO, Ontario Caregiver Organization

THE IMPACT OF COVID-19 ON CAREGIVERS. A COMPARISON OF YEAR ONE AND TWO

58%
of caregivers feel burnt out

61%
of caregivers find caregiving stressful overall, up from 49%

42%
of caregivers say their mental health is worse now compared to a year ago

23%
of caregivers say they are not coping well, as compared to 17% the year prior

46%
feel lonely, isolated, up from 43%

76%
are tired, up from 66%

64%
are anxious and worried, up from 57%

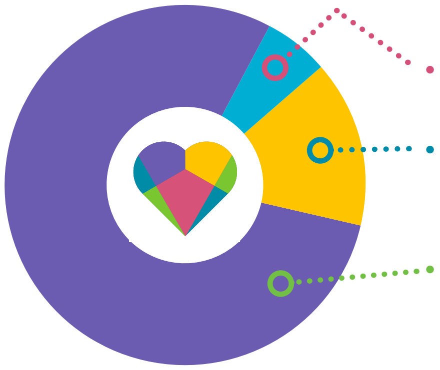
61%
are overwhelmed, up from 53%

53%
feel trapped, helpless and frustrated, up from 43%

45%
feel unappreciated, up from 39%

20%
took out a loan or line of credit to help pay for the expense, up from 17%

CAREGIVER PROFILE



6% have been providing care for Covid-19 related complications only

15% have been providing care for someone in past 12 months with added responsibilities due to Covid-19 complications

79% have been providing care for someone in the past 12 months for non-covid related health care issues

WHAT SUPPORT DO CAREGIVERS PROVIDE?

Caregivers support more than their family member or friend; they also contribute to Ontario's health care system by providing care to someone before and after a range of treatments. Whether they support the person for a short time or many years, they enable people to stay and age in their home, which is where they want to be. If you consider the average time caregivers invest in providing care and multiply it, even just at minimum wage, their efforts are the financial equivalent of an estimated 28.5 billion dollars per year.

82%
care for one person, usually an older family member, often a parent. Almost 1 in 5 are caring for more than one person

36%
of caregivers are supporting someone with problems associated with old age or frailty

46%
care for the person in the caregiver's home, 38% in the care recipient's home

FINDINGS: YEAR TWO OF THE PANDEMIC AND ITS IMPACT ON CAREGIVERS

THE ROLE IS HARDER:

Caregivers say their role has become much harder than it was last year. While all tasks are considered more stressful, caregivers find providing care and navigating supports amidst an over-extended health care system very challenging.

- Six in 10 (59%) say their responsibilities are more difficult now than before the pandemic, compared to 54% last year. Top 3 reasons:
  - Being at home all the time, the care recipient is unable to get important social interaction (38%)
  - Difficulty accessing the doctors and/or other healthcare professionals (36%)
  - Delayed/cancelled appointments require more time and effort in rescheduling (33%)
- Caregivers are also worried about:
  - Managing care recipient's anxiety due to Covid-19 (56%)
  - Finding services during Covid-19 (55%)
  - Keeping themselves and their families safe (57%)
- Those caring for child (75%), or spouse (70%) are most stressed overall
- 61% say the hours they spend providing care has increased, 34% invest 10+ hours of care per week as compared to 30% one year ago
- Women caregivers are more likely to say they are finding it difficult to manage caregiving during the pandemic compared to men (65% vs. 52%)
- 61% say they find caregiving stressful, a significant increase compared to 49% last year

> *"You have to be there to make sure things don't fall through the cracks. If you don't, you don't know what kind of care they are getting."*

- 75% say they have taken on responsibilities that would otherwise go to a personal support worker or nurse
- 26% had to send the care recipient to the hospital alone or were unable to provide care for the person in the care facility (22%) which added to the difficulty
- Even as Covid-19 restrictions are lifting, there is still a barrier to get the right kind of support, and at similar levels to what was seen last year. Costs for getting support continues to be the primary barrier
- Of those caregivers who spend more than 10 hours a week, 68% say they can only take a break occasionally (48%) or never (20%)
- More than half (55%) of those who are coping well can take breaks at least most of the time, of those not coping well, only 24% get the breaks they need
- 47% of caregivers can take the breaks they need; the other half can take a break occasionally (38%) or never (12%)
- 1 in 3 say they have no one to ask for help

> “*When you lose someone, you go through stages... you see them in the hospital to say good-bye. You have a funeral to grieve with loved ones. You have an interment for closure. But we had none of this. None. We couldn’t see them. We couldn’t celebrate them. It was a horrible experience.*”

CAREGIVER BURNOUT IS AT AN ALL TIME HIGH

While the majority of caregivers feel rewarded in their caregiving role, the added responsibilities continue to take a toll, with the number who are feeling tired, anxious, overwhelmed, trapped, frustrated and unappreciated increasing this year.

- 58% of caregivers say they are burnt out
- 42% of caregivers say their mental health is worse now compared to a year ago
- 23% caregivers say they are not coping well, as compared to 17% the year prior
- 46% feel lonely, isolated, up from 43%
- 76% are tired, up from 66%
- 64% are anxious and worried, up from 57%
- 61% are overwhelmed, up from 53%
- 53% feel trapped, helpless and frustrated, up from 43%
- 45% feel unappreciated, up from 39%

There is a significant decline in the number of caregivers who said they were coping “very well” – those coping very well drops from 22% to 16%, as do those coping physically 22% to 15% and emotionally 16% to 12%. These caregivers are predominately over the age of 65.

PROVIDING CARE IS MORE EXPENSIVE BECAUSE OF COVID-19:

There is a significant increase in the number of caregivers feeling the financial impact of caregiving, compared to pre-pandemic numbers (45% vs. 22%), with some having to pay for private care to cover the shortages they experience in facilities or homecare. One in five caregivers are using credit to pay for additional caregiving expenses.

45%
have experienced financial hardships this year, compared to 41% in 2020, and 32% in 2019 and 22% in 2018

47%
say due to covid-19 there have been more costs related to providing care

20%
of caregivers took out a loan or line of credit to help pay for the expense, up from 17%

WORKING CAREGIVERS STRUGGLE TO BALANCE RESPONSIBILITIES

Working caregivers who have been working remotely are worried about going back to work outside the home and are not sure how they will balance their caregiving and work responsibilities. While employers continue to be understanding, there has not been an increase in official caregiving policies. While working from home has added a level of flexibility that eases the caregiving balancing-act for some caregivers, most in this situation are concerned about the eventual return to the office. A third have considered leaving their role to provide more care to their family member or friend.

- 69% of caregivers work
- 67% of working caregivers are concerned about managing caregiving responsibilities when returning to work outside the home
- 74% of working caregivers have made alterations to their employment due to their caregiving responsibilities, slight increase from last year 69%
- Working from home continues to make a positive difference to caregivers
- 10% do not expect to return to work outside the home in the near future
- 7% took a less demanding job
- 1 in 3 believe employers understand their role
- 1 in 3 are worried about losing their job
- 30% have considered quitting to be able to take better care of their loved one
- More than half wish for more support from their employer
- Almost 2 in 5 have considered reducing work hours/taking a part-time job or quitting to better manage caregiving

> *“I have been working from home since March 2020. It has made it a lot easier. I can run down and check on my parents during the day... if they need me, I am there.”*

CAREGIVERS ARE CONCERNED ABOUT THE FUTURE OF HEALTH CARE

Caregivers find providing care and navigating supports amidst an over-extended health care system very challenging. That combined with staffing shortages is of great concern to caregivers. The majority feel if they weren’t present to help at the care facility their family member or friend would not get the same level of care. Some caregivers are paying for private care to cover the shortages they experience in facilities or homecare and most feel they are providing the type of care that would typically be provided by a nurse or personal support worker.

- Most caregivers feel their loved one is in the place they need to be – whether that is a private home or a healthcare facility. They also agree, regardless of where their loved one lives, the care they provide is comparable to that given by nurses and personal support workers, and that their caregiving lightens the load on the healthcare system.
- 63% say if they weren’t there to help at the healthcare facility, their loved one would not get the same level of care (65% in 2019)
- 85% are concerned about longer wait times
- 84% are worried about shortage of nurses
- 79% are concerned about less beds in hospitals
- 78% are worried about a shortage of personal support workers
- 75% are concerned about less beds in long-term care

Refer to Appendix A to learn what caregivers say they need to be successful in their role.

> *“I know you have to watch; you really have to advocate to make sure they get good care. But during COVID, you couldn’t. You weren’t there. You didn’t know what was going on. It caused me a lot of stress... a lot of worry.”*

> *“There is just not enough PSWs. They have so many patients to care for, they don’t have time...”*

FINAL THOUGHTS

For years, there have been organizations and caregivers working to shine a light on the challenges that caregivers face. What we knew was sometimes referred to as a crisis waiting to happen. At this stage of the pandemic, now is the time to act. With health care system transformation well underway, now is the time to engage caregivers and ensure they are involved in those aspects that affect them. However, this is not for the health care system to solve on their own. Employers, educators, family members, neighbours and friends can all make a difference.

To deliver on our mission of improving the lives of Ontario caregivers, we will continue to provide new and relevant information, programs as well as services that are designed in collaboration with caregivers so they feel supported in their role. We will continue to engage with caregivers across the province and amplify their voices to inform system-level decision making. We will also continue to collaborate with system partners to support caregiver engagement, and the uptake and implementation of valuable strategies and resources in their care setting. We will continue to raise awareness of the challenges caregivers face to build compassion and empathy and inspire us all to help one another. Our hope is that you will join us in our mission because we need caregivers and they need you.

WE CAN ALL MAKE A DIFFERENCE

We all know a caregiver and we can all do something to help. How?

You can learn more about the Ontario Caregiver Organization and its programs and services at ontariocaregiver.ca. You can also review the list below for ideas on what you can do to help. Contribute to the conversation by sharing other ideas on social using #wecanallhelpacaregiver. Be sure to tag @CaregiverON.

Are you a health care or community service provider?

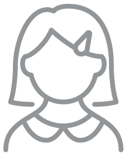
- Ask caregivers how they're doing. A simple "how are you" makes a difference
- Recognize and engage caregivers as essential partners in care, include them in decision making and provide them with the information they need to be successful. To the best of your ability, explain what they can expect next
- Check out resources on our website to support meaningful caregiver engagement and our Partners in Care Tool Kit created with health care providers and caregivers to help support access in care settings
- Take our e-Learning modules for health care providers, setting the foundations for building a culture of care partnerships
- Visit our dedicated page to find more resources to support care providers
- Collaborate with us on how we can support your organization in engaging caregivers as partners
- Refer caregivers to the Ontario Caregiver Organization to access programs and supports at ontariocaregiver.ca
- Refer caregivers to the 24/7 Ontario Caregiver Helpline at 1 833 416 2273 (CARE) to find resources in their area

Are you an Employer?

- Create a caregiver-friendly workplace by demonstrating your commitment to caregiver employees through enhanced HR policies, supportive conversations, and flexible work options
- Engage with your employees to identify caregivers in your organization and determine what they need to help balance work and caregiving
- Work with the Ontario Caregiver Organization to host training and information sessions for your managers and staff
- Check out our Guide for Employers and Employer e-Module to determine what strategies may be helpful in your workplace
- Share information about the Ontario Caregiver Organization; our 24/7 Helpline at 1 833 416 2273 and point them to resources available at

ontariocaregiver.ca including the Peer Support Programs and educational webinars

- Ensure they have access to information in your Employee Assistance Program
- Caregiving situations can change over time. Check in with your employee, ask how they're doing, it can make a difference



“It scares me to think of it. What happens when I need care? Who will care for me?”

Are you an Educator?

- Caregivers are children and youth too. Identify caregivers in your classrooms. Ask how they're doing. It can make a difference
- Provide reasonable accommodations to your students who are caregivers. Flexible deadlines, recorded lessons, and notetakers can help these students keep up with their education responsibilities while balancing their caregiver responsibilities
- Refer young caregivers to YoungCaregiversConnect.ca and the Ontario Caregiver Organization where they can access information, programs, and supports including the Peer Support Program

“I am the first of my friends going through this. My friends don't understand... they wouldn't know what to do.”

Are you a friend or neighbour?

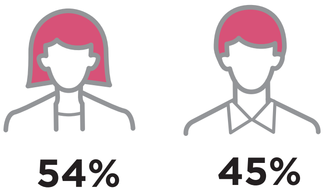
- Ask caregivers how they are doing. It's a simple thing that makes a significant difference
- Tell caregivers about the Ontario Caregiver Organization and let them know we have resources and programs that may help
- Offer practical help and support to the caregiver(s) you know. Caregivers are often reluctant to ask for help but providing practical or emotional support may make a significant difference. This could include errands, day to day tasks, providing food or a simple phone call to check in with the caregiver on how they are doing

DEMOGRAPHICS

Gender and Age

- Majority of caregivers are between the ages of 46 to 65 (41%).

GENDER



Non-binary/third gender – 1%

AGE – by Gender

2021	FEMALE	MALE	OVERALL
16-25	20%	15%	18%
26-35	13%	13%	13%
36-45	16%	17%	16%
46-55	18%	27%	22%
56-65	20%	18%	19%
66-75	9%	8%	8%
76+	4%	2%	4%

Marital status and Children

- Six-in-ten (59%) of Ontario caregivers are either married or have a common-law partner. 40% are single, of which 28% have never been married.
- More than half (56%) of caregivers are parents – 26% have children 17 or younger, and 35% have children that are 18 years or older.

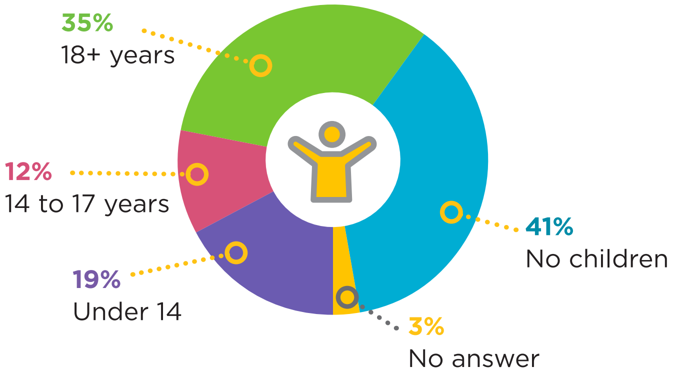
MARITAL STATUS

2021	
Married	47%
Living with common law partner	12%
Widowed	4%
Divorced	5%
Separated	3%
Single, never been married	28%
Do not want to state	1%

CHILDREN UNDER 14

55%	One
35%	Two
10%	Three or more

CHILDREN IN HOUSEHOLD



Respondents could choose more than one answer

DEMOGRAPHICS

Education and Household income

- Six-in-ten of Ontario’s caregivers have a University degree or higher (58%), while one-tenth (13%) have either a high school diploma or a lesser equivalent.
- 17% of caregivers in this survey have an average household income of less than $40,000. 28% have an income averaging $40,000 to $80,000. Almost one-in-three (29%) have a household income of greater than $100,000.

EDUCATION

TYPE OF EDUCATION COMPLETED	PERCENT
High school diploma or a high school equivalency certificate	13%
Less than high school diploma or its equivalent	3%
College, CEGEP or other non-university certificate or diploma	22%
Trade certificate or diploma	3%
Bachelor's degree	27%
University certificate, diploma, degree above the bachelor's	22%
University certificate or diploma below the bachelor's level	6%
PhD. or earned doctorate	3%
Prefer not to answer	1%

HOUSEHOLD INCOME

INCOME	PERCENT
Less than $40,000	17%
$40,000 to $59,999	13%
$60,000 to $79,999	15%
$80,000 to $99,999	14%
$100,000 and up	29%
Prefer not to answer	12%

> *It is work, but I call it a labour of love. I want to do it for them. I want to make sure they are taken care of.*

METHODOLOGY

An online survey was conducted among 801 self-reported caregivers in Ontario, 16 years of age and older. All participants answered "yes" to the following question:

During the past 12 months, have you cared for someone who needed support due to frailty, palliative care, long-term illness, long-term recovery from accident or surgery, degenerative disease, physical, mental health challenge or disability, or old age-related disorder? The need for this care could be due to Covid-19 diagnosis or be unrelated to it. 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, cooking meals, and feeding, bathing and toileting 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 psychological 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.

Surveys were conducted between September 24th to October 12th, 2021.

While quotas were put in place to ensure representation across demographics and region, results have been weighted to be reflective of the total population of caregivers in Ontario.

Margin of error is not applicable to this study due to its online methodology. However, as a guideline, the margin of error on a representative sample of 801 would be +/- 3.4%, nineteen times out of twenty.

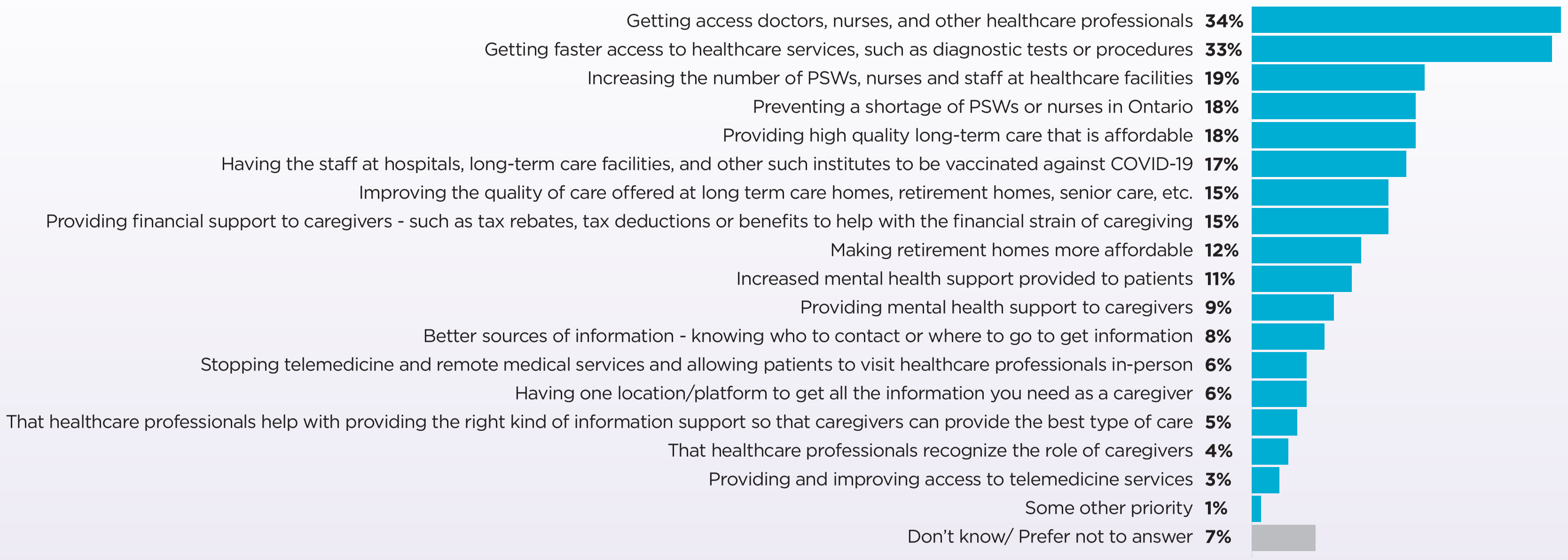
In addition to the online survey, a series of 10 In-Depth Interviews were conducted.

Respondents for this phase of the study were recruited from the quantitative portion of the research. Respondents in that phase were asked if they were interested in taking part in one-on-one interviews. Those who expressed interest were contacted, on a random basis, to take part in this research.

Respondents all met the criteria of being a caregiver, with a mix of age, gender, and caregiving situation (care receiver lived with them, in another private home or in a facility) taking part in the study.

APPENDIX A

INITIATIVES MOST NEEDED TO BE A SUCCESSFUL CAREGIVER



Q35. Which of these initiatives do feel you personally need the most right now to be successful in your role as a caregiver? Please select up to 3 options. (N=801)

Ontario Caregiver Helpline: 1-833-416-2273

Email: info@ontariocaregiver.ca
Phone: 416-362-CARE (2273) or 1-888-877-1626

www.ontariocaregiver.ca

Funded by:

Ontario

THE ONTARIO
caregiver
ORGANIZATION