



# Caregiving in Canada:

Challenges and opportunities shaping a national conversation

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The sessions provided valuable insights and helped us understand the varied and complex environment caregivers operate in today; and, it reinforced our belief that there is a need to raise awareness of family caregivers and the incredible work they do every day across Canada.

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The Petro-Canada *CareMakers* Foundation, including executive director Leila Fenc, with support from Impakt, Joanna Shnall and Dr. Adriana Shnall.



We believe that every family caregiver should feel cared for. By creating the Petro-Canada CareMakers Foundation™, we will have an opportunity to tangibly benefit charitable organizations throughout Canada who are working actively to support family caregivers.

Leila Fenc, executive director, Petro-Canada CareMakers Foundation

#### **Executive summary**

Caregiving is an issue that affects all Canadians. One in four Canadians is a caregiver for someone with a long-term health condition, disability or need related to aging at some point in their lives. It is estimated that 75% of care is provided by unpaid caregivers, saving Canadian healthcare systems billions of dollars per year. Our society simply would not function without caregivers.

More than ever before, Canada's caregivers are being recognized for their important contributions, yet meaningful support has been slow to follow. Furthermore, the significant contributions come at a high cost to caregivers, with extensive evidence revealing significant consequences to caregivers' health and well-being, prompting some to label caregiving as a public health issue. Financial consequences of caregiving, coupled with inadequate economic supports and labour policies, further add to their hardship.

We argue that supporting caregivers is of utmost importance, not only because support given to caregivers may help alleviate potential economic and health-related implications, but because caregivers are worthy of support regardless of the economic impact to society. The quality of their lives matter, and raising awareness of these issues will lead to improved outcomes.

# Petro-Canada CareMakers Foundation/ Fondation proches aimants Petro-Canada



Petro-Canada has recognized that caregiving is a national priority. In 2020, it established the Petro-Canada CareMakers Foundation/Fondation proches aimants Petro-Canada™, with the goal of increasing awareness of the importance of and need for caregiving, helping Canadians understand and realise the support they need to be effective care partners, and nurturing a national community of caregiving that recognizes the value of family and informal care partners.

This paper was developed based on cross-sectoral conversations with 29 caregiving experts, including healthcare professionals, service providers, researchers, employers, non-profit organizations, charitable institutions and caregivers with lived experience. The Foundation convened this group through a series of virtual roundtables to enhance the Foundation's understanding of caregiving. Stakeholders provided insight and recommendations on a range of challenges and opportunities facing Canadian caregivers. Roundtables were facilitated by Dr. Adriana Shnall, Program Director for Baycrest@Home Clinical Programs and the Koschitzky Centre for Innovations in Family Caregiving, Baycrest Health Sciences, and Assistant Professor (Status-Only) at the Factor-Inwentash Faculty of Social Work at the University of Toronto.

The guiding question for the roundtable discussions was:

"Given the almost universal need for Canadians to be caregivers or to be cared for during their lives, what are the opportunities to prioritize and better appreciate and fund this vitally important service?"

This paper focuses on the common themes that emerged across all discussions: awareness, access to education, training supports, information and resources; access to tailored and timely services; policies to recognize the role of caregivers; employment supports and financial concerns. This paper also builds upon the important work of Canadian organizations specializing in caregiving, including the

Vanier Institute, The Change Foundation and Carers Canada, among many others.

This discussion paper is a starting point for the important work that will be carried out by the Petro-Canada *CareMakers*Foundation/Fondation proches aimants Petro-Canada. It is our intent that this paper will be used to generate awareness of challenges faced by caregivers, highlight opportunities for meaningful intervention and serve as a tool to advance the cause of caregiving.



#### Introduction:

## Why should Canadians care about caregiving?

Being a caregiver, one of the biggest challenges is being able to care for myself. There's probably been a lot of times I haven't been well, but still had to be at work. Caregivers are often forgotten about, because they are giving care. They aren't out in the public. They're not socializing, they aren't going to social events, they're not able to participate with volunteer activities. Often after work, we're at home, we're providing care.

- Kevin, Canadian caregiver



Over half of Canadians, at some point in their lives, will provide unpaid care to a family member or friend with a long-term health condition, physical or mental disability or agerelated need<sup>1</sup>. Known as family caregivers, these individuals play integral roles in supporting relatives, friends and neighbours, yet too often go unrecognized and unsupported.

In Canada, it is estimated that 75% of care is provided by unpaid caregivers, which equates to approximately \$26-\$72 billion in unpaid work per year<sup>2,3</sup>. This reduces costs to healthcare systems, reduces pressure on home and community care services and allows individuals to receive the care they need in their own homes<sup>4</sup>. It is clear that without caregivers, Canada's healthcare and social systems would collapse.

The role of being a caregiver can be rewarding and meaningful, and not all caregivers report negative outcomes<sup>5</sup>. However, caregiving comes at a high cost to many who are in the caregiver role. Caregivers often experience multiple negative impacts on their physical health and psychological well-being <sup>6,7,8,9</sup>. In fact, the extensive evidence on the deleterious

consequences to caregivers' health and well-being has prompted some to view caregiving as a public health issue<sup>10</sup>. These outcomes have rippling effects which not only affect the caregiver, but may also affect health outcomes of care recipients<sup>11,12</sup>.

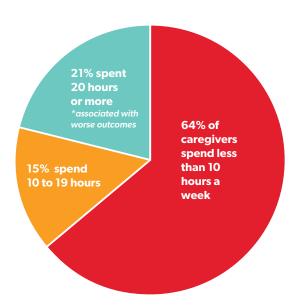
Caregiving has also evolved into a more complex, demanding and stressful role. 13 An increasing number of care recipients are requiring complex care, with more of this care being delivered at home. Despite having little to no formal training, caregivers are being tasked with managing complicated medical procedures such as providing wound care, caring for indwelling catheters, and giving injections. More than ever, caregivers are also juggling multiple competing roles: three-quarters of Canadian caregivers are employees<sup>14,15</sup>, many are parents raising families of their own, and as many as half provide care to more than one care recipient<sup>16</sup>.

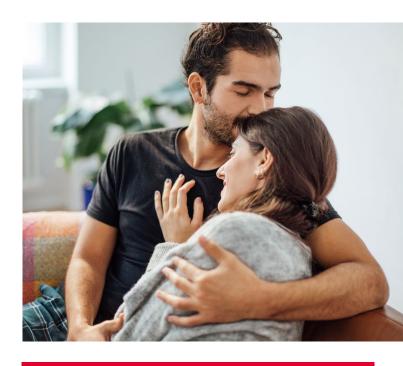
# Who are caregivers and what do we know about them?

We define a caregiver as someone who provides unpaid assistance to a relative, partner, friend or neighbour with a long-term health condition, a physical or mental disability, or problems related to aging<sup>17,18</sup>. We use the terms caregiver and family caregiver synonymously, and take an inclusive approach in defining family to include chosen family as well as traditional family relationships. It does not include child care, parenting, or care for individuals with minor short-term illnesses<sup>19</sup>. We refer to the person who is receiving care as a "care recipient."

The type of care provided, the level of intensity of the care provided, the duration of time spent in a caregiving role and the relationship with the care recipient are all important factors that influence the caregiving experience.

A 2018 Statistics Canada survey on caregiving<sup>20</sup> found that a majority of Canadian caregivers were between the ages of 45-64 (61%), almost half provided support to a parent or parent-in-law (47%) and spent an average of four hours per week on caregiving responsibilities (note: this figure jumps to 19 hours weekly for those providing care for older adults<sup>21</sup>). The most common tasks they assisted with included help with transportation (84%; includes running errands, helping with shopping, and attending medical appointments) and meal preparation and house cleaning (64%; see infographics for more detail).





## RELATIONSHIP BETWEEN CAREGIVER AND CARE RECIPIENT



47% provide care primarily for parents/parents-in-law



13% provide care primarily for close friend, neighbour or colleague (typically fewer hrs)



13% provide care primarily for spouse/partner



10% provide care primarily for an extended family member (typically fewer hrs)



8% provide care primarily for child with long-term health condition/ disability



9% provide care primarily for a grandparent (typically fewer hrs)

## Language used to describe caregivers

There are a range of different terms used to describe caregivers. As described above, we use the term *caregiver* to describe someone who provides care to either a family member or friend.

The term informal caregiver has been used to describe those who provide care without pay (and without formal training). However, this term is invalidating and inaccurate because it mischaracterizes the skill and complexity of the type of care that is provided by caregivers. Framing caregivers as informal may also perpetuate a lack of recognition and support for caregiver needs<sup>22</sup>. While differentiating between paid vs. unpaid caregivers can address this issue in some settings, it falls apart in other contexts where family caregivers are remunerated for their work (e.g. in the UK). An emerging understanding distinguishes caregivers (who provide care without pay) from care providers, who receive some form of pay or remuneration. Other terms used in other parts of the world to describe family caregivers include 'carers' and 'care partners.' There is more consensus in terms used to describe those who receive care as being care recipients.







## How caregivers see themselves

Adding to the complexity of this picture is how caregivers self-identify. Many caregivers do not see themselves as such for several reasons. First, many do not feel like they have a choice in assuming a caregiver role, viewing it instead as a familiar or cultural expectation or natural progression in their role as adult child, partner or parent. Similarly, shifting into a caregiver role may be a long and gradual process for some, and one without a clear starting point. There may also be a natural resistance to viewing oneself as a caregiver as it can be an emotionally-laden term, and a marker that things are changing.

Others may not identify as caregivers due to a social and systemic lack of awareness and recognition for who caregivers are and what caregivers do. In fact, less than half of caregivers believe that healthcare providers view them as being caregivers<sup>23</sup>. For example,

in the Canadian healthcare system, there is often an assumption that family members will assume caregiving duties. Yet there is often no formal recognition that they take on this role. Unlike in the UK, caregivers in Canada are not routinely assessed or supported in their own right<sup>24</sup>. In contrast, less than half of Ontario caregivers feel that healthcare providers see them in this light<sup>25</sup>. Without recognition for their role by formal systems, it is easy to understand why some do not identify as caregivers.

To overcome the complexities of language and identity, Statistics Canada defines caregiving based on the tasks that they do. In their survey, entitled "General Social Survey on Caregiving and Care Receiving," respondents are asked whether they have provided help with any of the following types of activities to a family member or friend with

a long-term health condition, physical or mental disability, or problem related to aging:

- personal care (such as assistance with bathing, toileting and dressing),
- medical care (such as assistance with medication management or wound care),
- practical support (such as assisting with finances, transportation, meal preparation, house cleaning, home maintenance or scheduling or coordinating care-related tasks)<sup>26</sup>.

It is important to note that this list is not exhaustive<sup>27</sup> (for example it does not include the provision of emotional support, which is a primary task provided by many caregivers<sup>28</sup>) and may not capture the full range of caregiver needs and experiences.



## Caregivers' diversity

Diversity amongst caregivers leads to a wide range of outcomes and adds another layer of complexity. Caregiving is not a singular experience and is shaped by multiple factors, some of which include age, gender, culture, race, ethnicity, language, immigration status, ability, sexual orientation, socioeconomic status and geography. Inherent in these conversations are issues of privilege and oppression, and it is necessary to consider how the intersection of these factors impact on caregivers' unique experiences.

For example, in an emergency room, a non-English speaking caregiver with mental illness is more likely to experience discrimination as a result of the *combination* of these two factors than if the caregiver only had to contend with a language barrier, or with a mental health issue. Efforts addressing caregivers' well-being must consider the impacts of intersectionality, and take impacts of systemic marginalization into account.



## Stigma associated with caregiving

Stigma can be related to many aspects of caregiving, including stigma surrounding some health conditions (e.g. mental illness), stigma around being unable to take care of oneself or provide care for a care recipient (e.g. due to depression or burnout), and stigma related to finances (e.g. discrimination against caregivers due to economic circumstances). As a result, it is common for caregivers to forego seeking necessary support.



## Different stages of caregiving create unique needs and considerations

Another important consideration is that there are multiple stages in a caregiver's experience, and that each stage has important implications on how a caregiver may be coping, and what it is most needed at that time. Caregiving can be viewed along a continuum with multiple stages that individuals traverse.

Individuals begin their experience at one stage,

and remain stable there or shift to another stage either gradually or suddenly. There are several ways to conceptualize this continuum: it could be mapped onto the trajectory of a specific illness. For example, a caregiver who is supporting an individual with progressive Multiple Sclerosis will move along a trajectory that parallels the progression of the disease, beginning at time of diagnosis

through to palliative and bereavement stages.

Stages can also be conceptualized based on where a caregiver is at, irrespective of the condition of the care recipient. The Vanier Institute conceptualizes the stages as ranging from: struggling (e.g. barely coping with a new diagnosis), to juggling (e.g. precariously coping with multiple tasks and stressors),

to *managing* (e.g. essential tasks are being managed with greater ease but caregivers still experiencing a lot of stress), to balancing (state of steadiness achieved leading to improved well-being), to *harmony* (e.g. optimally coping and able to give back).

Struggling Juggling Managing Balancing Harmony

The model has implications on how to best support caregivers at each stage (e.g. caregivers struggling to cope may be less able to make use of information about maintaining a healthy lifestyle, given that they are struggling with the most basic of tasks).

The stages are also non-linear, and can slide both forwards and back (e.g. illness progression can push a caregiver back to the struggling stage, no matter where they were on the continuum).



# Challenges and opportunities

## Awareness/recognition/creating visibility

It is very telling that despite nearly 1 in 2 Canadians (age 15 and over) reporting that they have provided care to someone in the past $^{29}$ , there remains lack of awareness about who caregivers are, what they do and the challenges that they face.

The complexities highlighted in the preceding section (language, self-identification, diversity and stigma) shed some light on the challenges. Yet in order to better support caregivers in this country, greater public awareness is required. Caregivers need greater recognition from family and friends, employers and healthcare systems and governments that they are overwhelmed and in need of support. Increased awareness could help to normalize and validate caregivers' experiences and reduce their sense of isolation.

Educating the Canadian public to recognize signs of caregiver stress and burnout in themselves, a family member or friend could lead to earlier intervention. Generating awareness of the importance of seeking help could lead to increased uptake in the use of supports. In short, awareness is essential to action.

There are several initiatives in Canada that focus on building awareness of caregivers' needs, for example Carers Canada celebrates a National Carers Day, on the first Tuesday of every April<sup>30</sup>. But awareness remains a significant challenge to be overcome. Until there is broader recognition and appreciation for caregivers, sustained support will remain difficult.





Different people are in different stages ... and certain things will resonate at different times along that continuum ... I think we have to be really careful when we're coming up with strategies and supports and resources for people, recognize that they're going through these steps.

- Nora Spinks, Vanier Institute



## Supports, services and programs

Caregivers require access to a variety of supports to address a range of physical, emotional, practical and self-care needs. Some examples include transportation services, meal delivery services, home care supports, respite services, day programs and healthcare services. However, in order to adequately address their needs, supports must be tailored to the unique circumstances of each caregiver and should be provided in a timely manner.

Caregivers are highly diverse, and one size does not fit all. In order to appropriately tailor supports, caregiver assessments should be conducted by healthcare and other professionals as part of routine care across

settings. Assessments should consider the condition of the care recipient, the emotional readiness of the caregiver and values, preferences and circumstances of the caregiver and care recipient. Given that needs change over time, caregiver assessment should be ongoing, with particular attention paid to critical transition points, with supports being adapted as required.

In addition to supports being tailored, they should be provided in a timely manner. Timely caregiver assessments completed early on in the care trajectory would enable earlier recognition of support needs and would facilitate more timely access to supports.

To put this in context and using the example of a caregiver of someone living with dementia, in the early dementia stages a comprehensive assessment should be conducted. Generally, at this initial time in the trajectory, people benefit most from tailored supports that focus on providing information about the diagnosis, supporting the caregiver around immediate needs such as income and employment-related concerns and short-term safety concerns. At this time, many caregivers are not ready for psychotherapeutic counselling; they actually feel they need concrete and appropriate resources. As these early, more basic needs are addressed, and when the caregiver is emotionally ready, the provision

of adjustment counselling can help the caregiver cope with the diagnosis.

As the illness progresses and needs change, re-assessment of the situation should be conducted, to assess what the current issues are and based on the assessment, new interventions can be recommended such as referrals to community programming, respite services and, if warranted, discussions around Advance Care Planning and long-term care.

#### Access to information, training and services

Caregiving is a very important area to support because there's not a lot of resources out there for it right now. And when people are in the role of caregiving, it's not something they are trained for, it just happens to you and there's a lot of things going on at the same time.

- Bruce, Canadian caregiver

There is no recognition of the skills that caregivers bring to the role, the learning that we do on the job, no recognition of that ... the caregiver role is considered to be almost a frill, associated much more with emotion than with actual need that are directly related to health outcomes.

Donna Thompson,
 Caregiver and Author The Caregivers' Living Room



Caregivers face challenges in accessing information and training. Having access to information is crucial, since it makes it possible for caregivers to plan and prepare for the future, and enables caregivers to be stronger advocates. However, information and training needs are often not adequately addressed by healthcare teams and often go unmet<sup>31</sup>.

While caregivers are often provided with information regarding the medical aspects of a particular condition, including information about treatment options, medications and signs and symptoms<sup>32</sup>, the majority of Canadian caregivers report lacking access to other forms of caregiver-specific information and education that would help them to feel better prepared to manage their caregiving duties<sup>33</sup>. This includes information related to financial and emotional aspects of caregiving, and finding appropriate services and support $^{34}$ .

Furthermore, when more information is needed, caregivers do not know where to turn and are more likely to depend on the internet or friends and family than they are on healthcare providers<sup>35</sup>. The difficulty with using the internet as a source of information is that individuals may not know which are the reputable websites, and a lot of misinformation can potentially occur.

Additionally, caregivers lack access to hands-on training to support the teaching of complex medical and personal care tasks. In addition to contributing to poorer caregiver outcomes, it also reinforces a lack of acknowledgement and validation of the skill that is required of caregivers. Handson training should become part of routine care across healthcare systems, to better equip caregivers in their roles and increase their confidence in the provision of care.



## Greater coordination is required

Healthcare and social service systems that provide caregiver supports are highly complex and fragmented. Furthermore, emerging caregiving initiatives across the country also tend to be disconnected from one another, leading to competition, overlap and redundancy across efforts. At the micro level, this results in difficulties navigating and accessing supports and uncoordinated service delivery 36,37.

At the macro level, it results in system inefficiencies and increased spending<sup>38</sup>. Organizations such as the Ontario Caregiver Organization are spearheading efforts to build greater coordination and collaboration across multiple sectors, and can serve as a model for how this can be accomplished.

#### Financial security and implications of being a caregiver

In Canada, the economic consequences of caregiving are an immense challenge, and financial support is the most significant need identified by caregivers. It is also reported to be the greatest barrier to caregivers accessing a variety of supports<sup>39,40</sup>. In fact, a 2019 Change Foundation Report found that one-third of Canadian caregivers faced financial hardships in the preceding 12 months due to caregiving responsibilities<sup>41</sup>.

One challenge is that caregiving impacts income. Not only are caregivers unpaid for the assistance they provide, in many circumstances they are also unable to work or must work reduced hours, leading to reductions in employment income with potential impacts on future career opportunities. For spousal caregivers, there

can a double financial threat: there is the loss of income of the care recipient, plus the loss of income for the caregiver due to having to stop or decrease hours of work. Moreover, the majority of people who are under 65 do not qualify for pensions, and are ineligible for income replacement programs.

In Canada, the most common form of financial support is through non-refundable tax credits. However, these non-refundable tax credits are less useful to low-income earners, as they may not have sufficient taxable income to claim the full amount of the credit. Furthermore, the tax credits are underutilized by those who do qualify, because they are difficult to navigate and are cited as being grossly inadequate to counter the economic consequences of

caregiving<sup>42,43,44</sup>. According to Statistics Canada, only 8% of caregivers reported receiving financial assistance through federal tax credits in 2018<sup>45</sup>.

The federal government administers the Family Caregiver Benefit and the Compassionate Care Benefit, which are income replacement programs offered through **Employment Insurance** (EI). They are designed for caregivers who require a temporary leave from work to provide care for someone who is critically or terminally ill, and are available to those caregivers who have made sufficient contributions to El in the previous 52 weeks. While important, additional benefits are warranted.

Another financial concern are out-of-pocket expenses.

Caregivers often incur significant expenses including costs related to transportation, medical supplies and professional services (e.g. personal support workers). While average out-of-pocket expenditures are reported to be modest for most caregivers, some caregivers incur substantial costs<sup>46</sup>. For example, a 2019 study completed by the Conference Board of Canada reported that caregivers for seniors spent an average of \$5,800 per year for out-of-pocket expenses<sup>47</sup>.

The caregiver compensation policies implemented in other countries including the UK, Germany, the Netherlands, Sweden, Australia and Japan could serve as examples for ways Canada could improve financial support for Canadian caregivers.

## Opportunity for support in employment and education spheres

Thirty-five per cent of the Canadian workforce are caregivers<sup>48</sup>. This is not surprising, given that 50% of caregivers are between the ages of 45-65 and in the prime of their careers<sup>49</sup>. When combined with the fact that 75% of caregivers are also employees, one can appreciate that there exists a major opportunity for action at the employer level.

Competing caregiving demands can lead to challenges in the workplace and can have negative financial consequences for the individual since caregivers may need to reduce work hours thus foregoing salary and benefits, may be unable to pursue career advancement opportunities,

or may exit the workforce altogether<sup>50</sup>. At a macro level, decreased job performance, increased rate of absenteeism and lost productivity also impact to the tune of \$1.3 billion annually<sup>51</sup>.

The benefits are not only financial: work can be an important source of respite for caregivers<sup>52</sup>. Policies that recognize and support diverse needs of employee caregivers can therefore lead to other positive psychosocial impacts.

Support for caregivers can come in many forms, including: education and training for leaders and staff to create supportive environments, flexible schedules and greater options for telecommuting,

workplace benefits, (including paid leave), and other targeted programs<sup>53</sup>. While many employers strive to support the needs of employee caregivers, very few organizations have formal policies or programs geared toward caregivers<sup>54</sup>. This therefore represents an important opportunity with the potential for widespread benefits.

INTERACTIVE LINK: CARER-FRIENDLY WORKPLACE STANDARD

INTERACTIVE LINK: WHEN WORK AND CAREGIVING COLLIDE Finally, education systems have an important role to play in supporting Canada's estimated 1.25 million caregivers aged 15-24<sup>55</sup>. Young caregivers attending school may not have the option to take a leave from school or reduce schooling hours. Yet they often need to miss school for caregiving tasks such as accompanying a care recipient to a medical appointment. Increased absenteeism, compounded with increased levels of stress, social and psychological difficulties, lead to higher rates of underachievement, and higher rates of high school dropout<sup>56</sup>. Supportive environments and tailored programs can lead to improved educational outcomes as well as improved health and psychological outcomes<sup>57</sup>.

The largest challenge we face is just navigating the different systems. You have to be adaptable and sometimes that can be pretty challenging, pretty taxing. So, to have more resources right at your fingertips, whether that's online or people that you can ask questions of, that would be incredibly helpful.

- Sheila, Canadian caregiver



#### **Caring communities**

Caregiving is a complex, multifactorial issue requiring involvement of multiple stakeholders. Although government and healthcare sectors have played a big role in this space, local communities are being increasingly recognized as important sources of support to bridge service gaps. Indeed, many of the supports that are crucial to caregivers are services that can be successfully delivered at the community level and do not require institutional support.

For example, networks of community members can support caregivers with tasks such as transportation or snow removal, and can leverage knowledge and support from others who have been through a similar situation. Organizations are spearheading important community initiatives and represent an opportunity to improve the caregiving experience.

## Considerations for a national caregiver strategy

There has been progress in advancing legislation that recognizes and supports the needs of caregivers. For example, Manitoba's Caregiver Recognition Act, 2011 and Ontario's Caregiver Recognition Act, 2018 call for greater recognition, awareness and support for caregivers. Quebec also recently introduced An Act to Recognize and Support Caregivers, 2020, and have recently appointed a Minister for Seniors and Caregivers.

A 2009 report by the Special Senate Committee on Aging concluded that addressing the needs of caregivers in Canada requires the development of a comprehensive caregiver strategy<sup>58</sup>. Yet 11 years later, Canada does not have a national caregiver strategy. This sets Canada apart from other developed nations (like the UK) that have implemented such strategies.

Many believe a national caregiver strategy in Canada could improve the lives of caregivers by formally recognizing their role, legislating policies to protect their rights, identifying priorities and actions that all governments, organizations and agencies can take, and providing funding for programs and services to address their needs. Specifically, the following components of a national strategy could address the challenges and opportunities outlined in this paper: a communications strategy to increase awareness about caregiving issues across Canada; increased funding for health and social services; creation of standards mandating assessment and service planning for caregivers; provision of more information, education, training supports; greater integration and care coordination; enhanced financial supports for caregivers and more supportive labour and education policies.



#### The time is now:

## Caregiving in the context of COVID-19

COVID-19 has had colossal impacts on virtually all elements of society. Caregivers in particular have been greatly impacted, as pre-existing financial, psychological, physical and social stressors (among others) have intensified. Caregivers have had to take on a greater share of caregiving responsibilities as medical care and home and community services have been forced to shut down or switch to offering virtual care. Physical distancing measures have also intensified social isolation and feelings of loneliness for many caregivers, with known consequences on health and even mortality<sup>59</sup>.

The pandemic has intensified the weaknesses (and strengths) of all systems, ranging from family and childcare systems, to healthcare, home care and long-term care systems. Yet amplifying the issues has also heightened awareness of the vital role that caregivers play in maintaining the status quo of these systems. Furthermore, the pandemic has presented us with a rare and urgent opportunity for action.

To date, Canada's COVID-19 Response has implemented changes that highlight the essential role of caregivers.

Most notably, the federal government has introduced a new caregiver benefit – the Canada Recovery Caregiving

Benefit – offering \$500 per week for up to 26 weeks for those required to take time off work to care for someone affected by COVID-19. Other significant examples include changes to long-term care policies which now formally recognize caregivers as essential care partners, and the tabling of a new Bill in the Ontario Legislature entitled *More Than A Visitor Act*, which if passed, would enshrine rights for caregivers of individuals living in institutional settings.







# Why a new Foundation in caregiving is needed

In 2018 alone, Statistics Canada estimated that approximately one-quarter of Canadians provided care to someone with a long-term health condition, disability or age-related need in the preceding year<sup>60</sup>. As highlighted above, caregivers are struggling and do not know where to turn. They need access to education, training supports, information and resources. They need effective services tailored to their own physical and emotional needs provided in a timely manner.

Fragmented systems require greater coordination nationwide, to reduce redundancy and cost, improve collaboration and most importantly reach those in need. Creating awareness about these issues is an essential part towards building supportive and caring communities.



Supporting caregivers is personal to us. Caregiving impacts our customers, our employees and our partners. With more than 1,850 retail and wholesale locations across the country, we are in a unique position to support Canadians to help reduce the invisibility of caregivers across Canada.

Deborah Gullaher, Vice
 President, Petro-Canada and
 Petro-Canada CareMakers
 Foundation board chair

We at Petro-Canada believe there is a foundation of caring that connects and holds Canadians together. For many, caring is more than a simple act of kindness; it is an everyday commitment to care for a relative, friend or community member with a health, disability or need related to aging.

The Petro-Canada CareMakers Foundation/Fondation proches aimants Petro-Canada has identified caregiving as a national priority and has made a long-term commitment to this important social issue. The primary purpose of the Petro-Canada CareMakers Foundation<sup>TM</sup> is to support caregiving across Canada.

Over the next 10 years, the *Petro-Canada CareMakers Foundation* will: create awareness and understanding of the issues of caregiving and inspire Canadians to help; raise funds and offer grants to support and amplify the work of caregiving organizations across Canada; and promote connection and collaboration among caregivers and diverse stakeholders to co-create meaningful caregiving innovations.

#### The caregivers among us







## Meet Cathy, a Canadian caregiver:

"Like many other Canadians, I have taken on the role of Caregiver in a situation where my mom was diagnosed with cancer. You couldn't get in-home nursing care. We couldn't get chemotherapy covered under the Ontario plan, because my mother was a resident of Nova Scotia. So the result was that there was so much time spent on the administration of my mother's health care, and navigating in-home nursing and transportation. It took away from my ability to focus on emotionally supporting my mother. When caregivers get into those situations, we then start to feel guilty about not spending the time and the focus of effort on what really matters. If more support had been available, it would have been invaluable.

Being a caregiver is a really stressful role, balancing your own family, balancing your work commitments, balancing your own well-being along with trying to be a health service provider, a personal support care worker, and someone who organizes transportation takes a tremendous toll on an individual, both mentally and physically. The fact that Petro-Canada wants to enter an arena where we are going to improve the lives of caregivers is a tremendous opportunity and extremely important."

## Meet Shaunna, a Canadian caregiver:

"In my life I am a caregiver for my daughter. She lives with severe autism, she requires 24-hour care, and our days our very repetitive, our care is very repetitive, so it feels like you don't get a break. I also care for my mother who is getting on in age and had been losing her mobility, so I take care of her as well. I think to have a break of any kind would be a small price and would go a long way in taking care of caregivers."

## Meet Alessandra, a Canadian caregiver:

"A few years ago, both my grandparents fell ill at the same time. Just watching your loved ones going through that and seeing them mentally and physically deteriorate day by day is heart wrenching. We were running around in circles in the beginning just trying to understand the processes. If we were given more information that would have meant the world to us. Even the day to day activities, meal prep, mowing the lawn, household management, some sort of service that would have helped in that area, we would have felt like we had more time with them.

If Petro-Canada was able to help caregivers like myself, I think they could make a tremendous impact. It would mean the world to so many people, even if it's just giving the gift of time, is priceless."





#### Conclusion

Caregiving is a near-universal experience but one that is felt and rarely seen. It is time to elevate awareness of the issues surrounding caregiving. By increasing recognition about the impact and needs of caregivers, together, we can reduce the invisibility of caregiving and recognize their invaluable role in Canadian society.



#### **Appendix**

Sinha, M. (2013). Portrait of caregiver, 2012: Statistics Canada. Retrieved from: https://www150.statcan.gc.ca/n1/pub/89-652-x/89-652-x2013001-eng.htm

2 Barylak, L. & Guberman, N. (2016). Beyond Recognition–Caregiving & Human Rights in Canada: A Policy Brief. Retrieved from: http://www.carerscanada.ca/wp content/uploads/2016/02/CCC\_Policy\_brief\_Human\_rights\_EN.pdf

3 The Change Foundation. (2019). Spotlight on Ontario's Caregivers Report 2019. Retrieved from: https://changefoundation.ca/spotlight-on-caregivers-report/

4 Statistics Canada. (2020). The Daily – Caregivers in Canada, 2018. Retrieved from: https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm

5 Schulz, R. & Sherwood, P.R. (2008). Physical and mental health effects of family caregiving. Journal of Social Work Education, 44(sup3), 105-113. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2791523/

6 Vanier Institute (2017). A snapshot of family caregiving and work in Canada. Retrieved from: http://vanierinstitute.ca/snapshot-family-caregiving-work-canada/

7 Hango, D. (2020). Support Received by Caregivers in Canada: Statistics Canada. Retrieved from: https://www150.statcan.gc.ca/n1/pub/75-006-x/2020001/article/00001-eng.htm#n1

8-10 Stall, N. (2019). We should care more about caregivers. Canadian Medical Association Journal, 191, E245-E246. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6400651/#b3-191e245

11 Cho, E. (2007). A proposed theoretical framework addressing the effects of informal caregivers on health-related outcomes of elderly recipients in home health care. Asian Nursing Research, 1(1), 23-34. Retrieved from: https://pubmed.ncbi.nlm.nih.gov/25030541/

12 Cho, E., Lee, N.J., Kim, E.Y. & Strumpf, N.E. (2011). The impact of informal caregivers on depressive symptoms among older adults receiving formal home health care. Geriatric Nursing, 32(1), 18-28. Retrieved from: https://www.sciencedirect.com/science/article/abs/pii/S0197457210004088

13 Stall, N. (2019). We should care more about caregivers. Canadian Medical Association Journal, 191(9), E245-E246. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6400651/#b3-191e245

 $\label{thm:continuous} \begin{tabular}{l} $1$ Government of Canada. (2015). When work and caregiving collide: How employers can support their employees who are caregivers – Report from the employer panel for caregivers. Retrieved from: http://www.nationalseniorsstrategy.ca/wp-content/uploads/2015/03/When-Work-and-Caregiving-Collide.pdf \end{tabular}$ 

15 Stall, N. (2019). We should care more about caregivers. Canadian Medical Association Journal, 191(9), E245-E246. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6400651/#b3-191e245

16 Health Council of Canada (2012). Seniors in need, caregivers in distress: What are the homecare priorities for seniors in Canada? Retrieved from: https://healthcouncilcanada.ca/files/HCC\_HomeCare\_FA.pdf

17 Family Caregiver Alliance. National Centre on Caregiving. Definitions. Retrieved from: https://www.caregiver.org/definitions-0

18 Turcotte, M. (2013). Family caregiving: What are the consequences. Retrieved from: https://www150.statcan.gc.ca/n1/pub/75-006-x/2013001/article/11858-eng.htm

 $\label{thm:continuous} \textbf{19} Government of Canada. (2015). When work and caregiving collide: How employers can support their employees who are caregivers – Report from the employer panel for caregivers. Retrieved from: http://www.nationalseniorsstrategy.ca/wp-content/uploads/2015/03/When-Work-and-Caregiving-Collide.pdf$ 

20 Statistics Canada. (2020). The Daily – Caregivers in Canada, 2018. Retrieved from: https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm

21 Stall, N. (2019). We should care more about caregivers. Canadian Medical Association Journal, 191(9), E245-E246. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6400651/#b3-191e245

22 Stall, N.M., Campbell, A., Reddy, M. & Rochon, P.A. (2019). Words matter: the language of family caregiving. Journal of the American Geriatrics Society, 67(10), 2008-2010. Retrieved from: https://onlinelibrary.wiley.com/doi/full/10.1111/jgs.15988

23-25 The Change Foundation. (2019). Spotlight on Ontario's Caregivers Report 2019. Retrieved from: https://changefoundation.ca/spotlight-on-caregivers-report/

26 Hango, D. (2020). Support Received by Caregivers in Canada: Statistics Canada. Retrieved from: https://www150.statcan.gc.ca/n1/pub/75-006-x/2020001/article/00001-eng.htm#n1

27 Battams, N. (2016). Family caregiving in Canada: A fact of life and a human right. The Vanier Institute of the Family. Retrieved from: https://vanierinstitute.ca/family-caregiving-in-canada/

28 The Change Foundation. (2019). Spotlight on Ontario's Caregivers report 2019. Retrieved from: https://changefoundation.ca/spotlight-on-caregivers-report/

29 MacCourt, P. & Krawczyk, M. (2012). Supporting the caregivers of seniors through policy: the caregiver policy lens. Vancouver, BC: British Columbia Psychogeriatric Association. Retrieved from: https://www.msvu.ca/wp-content/uploads/2020/05/Caregiver20Policy20Lens.pdf

30 Carers Canada. (2017). 2017 National Carers Day. Retrieved from: https://www.carerscanada.ca/nationalcarergiverday/

31 The Change Foundation. (2019). Spotlight on Ontario's Caregivers report 2019. Retrieved from: https://changefoundation.ca/spotlight-on-caregivers-report/

#### **Appendix**

- 32 34 National Institute on Ageing. (2018). Why Canada Needs to Better Care for Its Working Caregivers. Toronto, ON: National Institute on Ageing White Paper. Available at: https://www.ryerson.ca/nia/commentary/caring-for-working-caregivers/
- 35 The Change Foundation. (2019). Spotlight on Ontario's Caregivers report 2019. Retrieved from: https://changefoundation.ca/spotlight-on-caregivers-report/
- 36 Stall, N. (2019). We should care more about caregivers. Canadian Medical Association Journal, 191(9), E245-E246. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6400651/#b3-191e245
- 37 The Change Foundation. (2019). Spotlight on Ontario's Caregivers report 2019. Retrieved from: https://changefoundation.ca/spotlight-on-caregivers-report/
- 38 Canadian Nurses Association. (2013). Three strategies to help Canada's most vulnerable. Retrieved from: https://www.cna-aiic.ca/~/media/cna/files/en/pre\_budget\_brief\_to\_house\_of\_commons\_2013\_e.pdf
- 39 Hango, D. (2020). Support Received by Caregivers in Canada: Statistics Canada. Retrieved from: https://www150.statcan.gc.ca/n1/pub/75-006-x/2020001/article/00001-eng.htm#n1
- 40-41 The Change Foundation. (2019). Spotlight on Ontario's Caregivers report 2019. Retrieved from: https://changefoundation.ca/spotlight-on-caregivers-report/
- 42 Stall, N. (2019). We should care more about caregivers. Canadian Medical Association Journal, 191(9), E245-E246. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6400651/#b3-191e245
- $43\,$  National Institute on Ageing. (2018). Why Canada Needs to Better Care for Its Working Caregivers. Toronto, ON: National Institute on Ageing White Paper. Available at: https://www.ryerson.ca/nia/commentary/caring-for-working-caregivers/
- 44 Canadian Centre for Elder Law. (2010). Chapter Five Indirect Compensation of Caregivers through the Tax System. Retrieved from: https://www.bcli.org/elder-law-resources/execsum/chapter5
- $\label{eq:45} \textbf{Statistics Canada.} \ (2020). \ The \ \textbf{Daily-Caregivers in Canada.} \ 2018. \ \textbf{Retrieved from: https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm}$
- $46\,\text{Fast}$ , J., Eales, J. & Keating, N. (2018). Informal Caregiving: What Are the Financial Costs for Caregivers? CRDCN Synthesis Series. Retrieved from: https://crdcn.org/sites/default/files/financial\_costs\_of\_family\_caregiving.pdf
- 47 Heschl, C. & Arcand, A. (2019). Measures to Better Support Seniors and Their Caregivers.

  Ottawa: The Conference Board of Canada. Retrieved from: https://www.cma.ca/sites/default/files/pdf/health-advocacy/Measures-to-better-support-seniors-and-their-caregivers-e.pdf

- 49 Canadian Caregiver Coalition. (2015). Tips & Tools for Employers: Supporting Employees to Balance Care and Work Responsibilities. Retrieved from: https://www.carerscanada.ca/wp-content/uploads/2015/09/CCC-Care-Work\_tips-tools-employers\_v7.pdf
- 50 Stall, N. (2019). We should care more about caregivers. Canadian Medical Association Journal, 191(9), E245-E246. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6400651/#b3-191e245
- 51 Health Council of Canada (2012). Seniors in need, caregivers in distress: What are the homecare priorities for seniors in Canada? Retrieved from: https://healthcouncilcanada.ca/files/HCC\_HomeCare\_FA.pdf
- 52 Joseph, G. & Joseph, A. (2019). Exploring employment as a space of respite and resistance for family caregivers. Health & Social Care in the Community, 27, 1481–1489. Retrieved from: https://onlinelibrary.wiley.com/doi/abs/10.1111/hsc.12819?af=R
- 53 Canadian Caregiver Coalition. (2015). Tips & Tools for Employers: Supporting Employees to Balance Care and Work Responsibilities. Retrieved from: https://www.carerscanada.ca/wp-content/uploads/2015/09/CCC-Care-Work\_tips-tools-employers\_v7.pdf
- 54 Government of Canada. (2015). When work and caregiving collide: How employers can support their employees who are caregivers Report from the employer panel for caregivers. Retrieved from: http://www.nationalseniorsstrategy.ca/wp-content/uploads/2015/03/When-Work-and-Caregiving-Collide.pdf
- 55 Young Caregivers Association. (2020). Who Are Young Caregivers? Retrieved from: https://youngcaregivers.ca/who-are-young-caregivers/#canadian-overview
- 56 Ontario Caregiver Organization. (2020). Young Caregivers. Retrieved from: https://ontariocaregiver.ca/resources-education/caregiver-resources/young-caregivers/
- 57 Young Caregivers Association. (2020). Who Are Young Caregivers? Retrieved from: https://youngcaregivers.ca/who-are-young-caregivers/#canadian-overview
- 58 Carstairs, S. & Keon, W.J. (2009). Special Senate Committee on Aging, Final Report. Canada's Aging Population: Seizing the Opportunity. Retrieved from: https://sencanada.ca/content/sen/Committee/402/agei/rep/AgingFinalReport-e.pdf
- 59 Holt-Lunstad, J., Smith, T.B., Baker, M., Harris, T. & Stephenson, D. (2015). Loneliness and social isolation as risk factors for mortality: a meta-analytic review. Perspectives on psychological science, 10(2), 227-237. Retrieved from: https://journals.sagepub.com/doi/pdf/10.1177/1745691614568352?casa\_token=VgvE1X78YNUAAAAA:\_
  vT6b93eRT7fMRKirwndsWc9PHeyNMHb5avps4V\_8ek0oGqjk9WAwsc\_WsH7KRqGzYBLD6OGVTuh
- 60 Statistics Canada. (2020). The Daily Caregivers in Canada, 2018. Retrieved from: https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm