

## CAREGIVERS NOVA SCOTIA ASSOCIATION

Submission to:

The Canadian House of Commons' Standing Committee on the Status of Women on the topic of the Economic Security of Women in Canada

Submitted by:

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### INTRODUCTION

Thank you for the opportunity to provide a voice for Nova Scotia women who are experiencing economic insecurity as a result of giving unpaid care to a loved one.

Caregivers Nova Scotia recognizes that since the formation of this committee the federal government has made a budget announcement that will benefit caregivers and especially women. We commend the Government on moving forward, but we also realize that these measures will benefit women in the future, although not necessarily women who currently find themselves economically insecure.

Caregivers Nova Scotia was the first province-wide caregiving organization in Canada. The idea was born in the early '90s by a group of women sitting around a kitchen table discussing the need to support unpaid family and friend caregivers. In the ensuing years we have established our four pillars of Information, Support, Education, and Advocacy, all delivered within the context of evidence-based research and caregiver requested services.

Our organization receives operational funding from the Nova Scotia Department of Health and Wellness, Continuing Care Branch, and project funding from various sources such as the Nova Scotia Department of Seniors.

### LANGUAGE

It is important to first address language. When we refer to "caregiver", we are referring to someone who, either at home or in a facility, gives unpaid care to a loved one who has a physical or mental health condition, or who is chronically ill, frail, or elderly. Caregivers may be spouses, adult children or in-laws, parents, siblings, youth, extended family members, friends, or family of choice. It is

important to distinguish caregivers from others due to psychosocial factors that affect them.

A “Care provider” is a person who provides care and receives a salary or wage for their time. Care providers can range from a home care worker or personal care worker who requires Continuing Care Assistant (CCA) certification in Nova Scotia, to a healthcare professional such as a nurse (LPN, RN, NP), occupational therapist (OT), physiotherapist (PT), dietician (DT), physician (MD), and other licensed clinical professionals. They may be employed, self-employed, or contracted. They are entitled to vacation, statutory holidays, benefits, and pensions.

Historically academia and government have often referred to caregivers as “informal caregivers”. Although caregivers have not been formally trained and do not give care in a formal setting such as a hospital, there is nothing informal about what they do. They have repeatedly requested that this term not be used to describe them. They state that it is insulting. We agree with them.

It is also important not to refer to caregivers as “volunteers”. Unlike volunteers, caregivers have few choices as to when or where they give care.

## OUR ORGANIZATION

Caregivers Nova Scotia currently has a staff of seven who provide confidential individual phone and email support, healthcare system and community information, 21 monthly in-person support groups, and educational workshops that focus on caregiving. Everyone at our organization is or has been a caregiver. We have a membership of more than 4500 caregivers and supporters.

Our caregivers look after loved ones with a wide range of illnesses and conditions. Caregivers face challenges, physical, emotional, and financial. Many of our caregivers have had to quit full time employment, reduce their hours of work, or use up vacation and sick time in order to fulfill their caregiving duties and responsibilities.

In reviewing the briefs that have been presented to this committee over the past several months, we have read some compelling data.

We have, however, chosen to take a different path in the information we present. Ours will be the first-voice of the women we serve everyday. It will also be our own voices, as the six women who work at Caregivers Nova Scotia are working caregivers and know these issues firsthand.

## ENVIRONMENT

Giving unpaid care to a loved one is invisible work, often unacknowledged, and sometimes thankless. No time clock is punched, productivity is not traced or measured, and remuneration is not calculated. Furthermore, workplace safety is not taken into consideration, and little or no training is provided. Yet 31% of Nova Scotians are giving some form of care. To further illustrate the value of unpaid caregiving, a study conducted by the Canadian Institute for Health Information found that 98% of seniors receiving Home Care services could not continue to age safely in place without the support of a family member or friend giving unpaid care.

Nova Scotia is unique amongst other Canadian provinces in that we have government programs that can assist eligible caregivers: the Caregiver Benefit of \$400 per month; and, the Supportive Care Program of \$500 per month, with a possibility of an additional \$495 annually for snow removal.

The Caregiver Benefit is non-taxable, but it is reportable and can affect federal Guaranteed Income Supplement benefits. It is income tested and is intended for caregivers of lower income adults who have a high level of disability or impairment.

The Supportive Care Program is non-reportable and, therefore, non-taxable. It is meant to assist with home support services for caregivers of people with cognitive impairments. It may be used for personal care, respite, or meal preparation and household chores. The \$500 per month is not income tested. The \$495 per year is income tested.

Currently there are approximately 1900 Nova Scotians receiving the Caregiver Benefit and 320 on the Supportive Care Program. In our opinion, these numbers are low, especially for the Supportive Care Program. We regularly hear from caregivers who are frustrated by the inaccessibility of these programs – many are unaware of their existence until we inform them – and by the inconsistent application of eligibility requirements by Continuing Care Assessors. We have assisted numerous caregivers appeal negative decisions, and most have been successful with their appeals.

There are also a number of delays involved with Continuing Care. On average clients wait 56 days for service, and one third of these are waiting to be assessed or re-assessed. Unpaid caregivers fill these gaps in service but at an emotional and financial cost. Further delays are experienced when someone is deemed eligible for Long Term Care, as there are few beds available. These delays often postpone the possibility of a caregiver returning to work.

## THEMES

### 1 - Lack of self-identification

One of the greatest barriers to caregivers accessing programs and services is their reluctance to self-identify as a caregiver. We often hear, “I’m his wife” or “She’s my mother”, without “and I’m the primary caregiver”. In the past few decades, the working environments of women and the physical and emotional demands of families have changed significantly. Most families cannot survive financially without all adults engaged in paid work, and caregivers are often faced with supporting and managing two homes – their own and that of their care recipient – while working and raising children.

## 2 - Women’s roles as caregivers

Although women continue to represent the majority of caregivers (54% according to Statistics Canada) male caregiving and female caregiving typically differ in the type and intensity of the care given. Women continue to spend more time on housekeeping, meal preparation, personal care, and medical care – all which tend to be time-consuming and allow for less flexible scheduling. This is an important theme to reiterate, as we hear it every day from our caregivers.

The oldest or unmarried daughter is often the first choice as primary caregiver, although sometimes proximity dictates which daughter will be in this role. In many cases when a daughter is unavailable, a daughter-in-law is expected to take on the role. Whether the pressure to step up is societal or self-imposed, it can be overwhelming, and there are few options for those women who do not wish to be caregivers or who are not personally suited to the role. We have some caregivers who have been abused by their care recipients, including physical or sexual abuse, but are expected to give care to them in their senior years.

Some women find it impossible to support and maintain their own home during caregiving and move in with their care recipient, usually when the care recipient refuses in-home services or suggestions of moving to Long Term Care. The move to an aging parent’s home, while ensuring the senior is safe, results in missed equity accumulation in the caregiver’s own home. When the parent dies, estates are more often than not split equally amongst siblings, with no additional provision for the caregiver who has sacrificed not only her income but also her own secure housing.

## 3 - Financial Expenses

Out-of-pocket expenses can be unexpected and burdensome, sometimes increasing imperceptibly over years of caregiving. Caregivers have reported making substantial contributions each month by subsidizing groceries, rent, medication, transportation, equipment, or privately contracted home care. Even something as simple as a specialized diet can be out of reach for a care recipient living on a fixed income, so that too falls to the unpaid caregiver.

Technological connectivity (internet and cell phone) is a costly yet vital tool for communicating with family members, for learning about the characteristics of a

medical condition, or for accessing resources such as instructional videos for hands-on caregiving.

Smaller-sized families and geographic separation due to seeking education or employment away from one's family means that some of the women we support have become long-distance caregivers. This is true even where other family members may live close by but, for any number of reasons, are unable or unwilling to contribute to the family member's care. Transportation costs for a long-distance caregiver to visit their care recipient can be substantial.

Over time, such out-of-pocket expenses incurred through travel, phone calls to support the family member or friend, or to help arrange medical appointments or deal with financial or legal matters, add up.

The expectation may be that women who move away from their parents plan for a future with ill or aging parents in mind, that they put money away that will go towards expenses specific to long-distance caregiving which can range from hundreds of dollars a month, to thousands of dollars per year depending on the distance. Yet it is women who are the majority in low-wage, minimum wage, or precarious work. Their own families or other commitments will make it financially impossible for them to put money away for such expenses, never mind move in with or near her parents to fulfill her caregiving responsibilities.

For a woman who wants and chooses to be a long-distance caregiver, and who wants and chooses to retire from work to move closer to their loved one to help care for them, is it reasonable to expect that she do so with little or no means of support from government or employers, and with no help for her to return to work afterwards? Is it reasonable that a daughter earning less than her brother or male counterpart and who may be in precarious employment circumstances and who may have fewer pensionable earnings to draw on, be expected to take on this burden without help?

Respite care may be hired individually or through a private home care agency. Costs can range from \$15-\$30 per hour and are out of reach for the majority of caregivers. It should be noted, however, that respite services are not available in many rural or remote areas of the province. In addition, some caregivers have been told by Home Care Assessors that as long as they can leave their care recipients for even short periods of time, or if they go to work, they will be denied access to respite and other programs.

Adult Day Programs are offered in 35 communities across Nova Scotia, providing both much needed respite opportunities for the caregiver and social and recreational programming for the care recipient. At an average cost of \$25 per day, many of these programs are unsuitable for providing respite for working caregivers as they typically run 1-3 days per week and between 9am-2pm.

Many female caregivers have left the workforce early, negatively affecting their income for the rest of their lives. They have expressed fear of living in poverty during their own old age, because they have lost pensionable years to unpaid caregiving, especially in the latter years of their career when income is typically at its highest. Early retirement leaves the caregiver in the precarious position of eventually being financially dependent on her children, if she has children.

To accommodate their caregiving demand, some women have been forced to take casual or non-standard jobs that offer little security or predictability. Still others have had to forego promotions, scale back on hours worked, or accept lower paying employment that offers more flexible hours.

#### 4 – Working Caregivers

Most female caregivers who are able to continue working have reported elevated stress as their responsibilities increase. The few who work in a caregiver-friendly environment still carry guilt over missing time, increasing the workload for colleagues, and not being there for clients. For those who do not have understanding employers, the result can be that the caregiver is at work but brings decreased energy and engagement as well as relentless distraction from her caregiving responsibilities.

Caregivers have told us that they use all of their sick, personal, and vacation time for medical appointments, giving hands-on care at home, running errands, and waiting for medical services. Some give care from a distance and visits to check on how the care recipient is doing involve additional time for travel. We all need the benefit of rest and relaxation, returning to work renewed and re-energized. However, caregivers often return from time off worn out, frustrated, resentful, and guilty over feeling that they aren't doing enough. Productivity suffers.

In an unsupportive workplace, the caregiver may also feel the stigma of being called away from her job. Body language and remarks from co-workers about frequent absences contribute to building her unrealistic and unachievable expectation that she must do all things well, both her work and family obligation. Over time, this situation worsens. In the absence of flexible caregiving policies she is not able to succeed in both roles.

#### 5 - Caregiver Returning to Workplace

The caregiver returning to the job market can find her skills out-dated, especially if caregiving has spanned several years. In addition, the window between the death of her loved one and returning to work, while managing her grief, is often short and there are no designated programs to assist with this transition.

But even more devastating to employment re-entry is the caregiver's state of health. Clients have expressed surprise when, after the death of their loved one,

they are diagnosed with their own chronic medical condition. Often, the medical condition has been long-standing but undetected as the caregiver has focused on the health of the care recipient with little or no regard for her own health. Simply put, she has felt so tired and ill for so long it has become her ordinary state of health.

Some of the issues experienced by our clients include shoulder, neck, and back injury from lifting and supporting, mental illness due to prolonged intense stress, diabetes, hypertension, chronic digestive issues, and debilitating mobility impairments from deferred hip and knee replacements. Some women caregivers have reported postponing treatment for pre-existing conditions because there was no one to step in while she sought medical attention. In poor health herself, she is unable to bounce back quickly. She loses confidence in her ability to contribute productively to a workplace.

One of our clients phrased it well when she compared caregiving to being sent to war ill-equipped. She was conscripted rather than volunteered, she was not trained for the task, didn't have the correct equipment, was dropped off in unknown territory for an unspecified period of time, unfamiliar with the enemy. There will be no transitional programs or supports for her when she returns to her own life.

## **RECOMMENDATIONS**

Caregivers Nova Scotia respectfully requests the consideration of the following recommendations.

### **1. Create a financial assistance program for caregivers**

Caregivers who must leave their job should be afforded a guaranteed basic income to cover some of their personal expenses while away from the workplace. Funding for this program could be offset by savings of approximately \$2800/month which is the cost of Long Term Care in Nova Scotia and up to \$110 per day for an alternate level of care bed. The creation of a guaranteed basic income would allow women caregivers to respond to federal and provincial government messaging on aging in place.

### **2. Create workplace accommodation for caregivers**

There is a need for workplace flexibility to allow the integration of unpaid care and paid work responsibilities. Caregivers consistently flag flexibility in the workplace as key to help them manage, and although flexible working options exist for some, one-size-fits-all policies don't work.

Job protection ensuring job security and no penalties (e.g., demotion, loss of benefits) for a prolonged absence while giving care needs to be standardized across the country.

In addition to the federal government's Employment Insurance programs and the provincial Labour Standards, we at Caregivers Nova Scotia also provide up to 5 days of <sup>1</sup>paid leave, after personal days have been used, in conjunction with any leave for Employees to provide care or support to a family member with a serious medical condition, defined as "Caregiver Leave".

### **3. Increase the number of Continuing Care Assistants/Home Care Workers**

Offer bursaries and non-repayable loans to those motivated to become CCAs. In particular, tap into the new pool of talent - unpaid caregivers who are no longer giving care - as they expand on the skills they have developed in their personal lives. Utilize Prior Learning Assessment Recognition (PLAR) to move them through accreditation and into paid work more quickly.

### **4. Improve Adult Day Programs frequency and funding**

Extend Adult Day Programs to 5 days per week and 8+ hours per day, allowing caregivers to continue working and contributing to their household income and to their pensions.

Subsidize Adult Day Program spaces by offering a sliding-scale payment option.

### **5. Find different approaches to ensuring long-term financial security for those leaving their workplace to give care.**

For those caregivers who must leave their paid employment to respond to caregiver demand, a methodology should be developed as a means of preventing significant loss of income in their senior years.

### **6. Continue to publish hard copies of resources.**

Not everyone has access to the internet and not all resources are suitable for printing at home, such as The Caregiver's Handbook. The trend by governments to cease supporting hard copy publishing is myopic as it can further marginalize some people, especially caregivers with limited income. For the record, Caregivers Nova Scotia mails out our bi-annual newsletter to about 450 caregivers who do not have internet access.