Caregivers Nova Scotia Association  
Written Submission to the Standing Senate Committee on Social Affairs, Science and Technology  
The Issue of Dementia in our Society

Caregivers Nova Scotia, the first province-wide caregiving organization in Canada, was officially formed in 1998 but unofficially started a few years earlier by a group of women sitting around a kitchen table who realized that unpaid family and friend caregivers needed help.

Since that time we have expanded to a staff of seven providing individual phone, email, and in-person support and system navigation. We hold 20 monthly support groups and deliver educational workshops across the province. Everyone at Caregivers Nova Scotia is or has been a caregiver. We have almost 4,000 members.

We support all caregivers including people who are caring for loved ones with Alzheimer’s disease and other dementias, cancer, multiple sclerosis, ALS, autism, diabetes, and other chronic conditions. Many of our members are looking after someone who is frail and elderly, while others are giving palliative care.

Some of our caregivers are able to continue to work. Others have had to quit their jobs or retire early. Some have had to move back to Nova Scotia to look after their parents. The majority speak of financial challenges.

Some of our programming in Nova Scotia is unique in Canada, and how we support caregivers is what I would like to highlight.

I would like to begin with how our provincial government, regardless of the party in power, offers two unique benefits to lower income families: the Caregiver Benefit and the Supportive Care Program. The Caregiver Benefit recognizes the important role of caregivers in their efforts to assist loved ones and friends. Those who qualify can receive a benefit of $400 per month. Currently there are about 2,000 caregivers receiving this benefit. The Supportive Care Program supports eligible Nova Scotians with cognitive impairments by providing them with $500 per month for Home Support Services. There are currently about 300 people receiving this benefit.

The Nova Scotia Department of Health and Wellness also funds Caregivers Nova Scotia’s operational budget.

Our educational workshops are all delivered from the caregiver perspective and can be divided into three categories: skills acquisition, event preparation, and self-care.

The first category of skills acquisition is the result of caregivers reporting that they feel unprepared for certain tasks, and we fill two of the most commonly expressed gaps. In conjunction with a community pharmacist, we deliver a Safe Medicines for
Seniors and Caregivers workshop. We also offer a Brushing Up on Mouth Care workshop that includes dementia care and palliative care.

The second category of education is preparing caregivers for certain events. In response to requests from our caregivers, we have created an Advance Care Planning for Caregivers workshop that is modelled on the national Speak Up campaign from the Canadian Hospice and Palliative Care Association. This workshop instructs caregivers on what an advance care plan is, why it is important, how to start the conversation with family, friends, and a healthcare provider, and the documents required to make their wishes legal.

Last year Caregivers Nova Scotia partnered with the Canadian Red Cross Nova Scotia Division to develop a Disaster Preparedness for Caregivers workshop. Still in the pilot phase, it addresses developing kits for a 72-hour emergency, and learning about evacuation centres.

The third category is self-care, which is the most important aspect of caregiving but almost always the lowest priority on a caregiver’s list. When I speak with caregivers, I often repeat the announcement given by flight attendants about putting on one’s own oxygen mask first. It is necessary for caregivers to look after themselves before they are able to help anyone else. But this may seem impossible especially if their loved one requires a great deal of care.

As part of self-care, caregivers need to learn skills for coping with their situations. My organization has developed a 3-hour Caregiver Stress Management workshop that helps caregivers identify common stressors and address them before they become harmful to their health. We focus on strategies to help them regain and maintain their life balance.

As stated previously, my organization holds 20 monthly in-person support groups. As with our educational workshops, support groups are open to caregivers of all diseases, conditions, and situations, and not just dementia.

Research has shown that caregivers experience loneliness and isolation. Caregivers self-report that friends and family stop calling and visiting. It is important to the caregiver’s own mental health and wellness to build a supportive social network. A peer support group can be the right mechanism to promote on-going self-care.

In our experience a diverse group of peers can be particularly helpful. When caregivers are given the opportunity to change their focus away from their care recipient’s disease to themselves, they talk about their challenges and joys, their concerns, and their communication issues. They are able to share their experiences with others who are or may have been in similar situations, and learn from one another. This philosophy is shared with other caregiving organizations such as Caregivers Alberta and Family Caregivers of British Columbia.
Many of our members also attend other support groups such as those offered by the Alzheimer Society of Nova Scotia. This is a good thing as it demonstrates that both models of support are valuable – one disease-centric and one caregiving-centric.

Caregivers Nova Scotia recognizes that not all caregivers are able to attend in-person support groups. This may be due to transportation, mobility, lack of respite, or discomfort with leaving their loved one. In the fall of 2014 we piloted a research project called Caregiver TeleGroup Support, two teleconference-based facilitated support groups. It was a successful project and further research funding is pending.

Family and friend caregivers have needs that are unique to their caregiving journey. Along the continuum of care, as the care recipient’s needs change, so probably will the support requirements for the caregiver.

Caregiving does not end if a loved one enters a long-term care facility. Many caregivers visit daily, even multiple times, to assist with meals, bring required items, and to keep people company. Often they assist with other residents too.

Being a caregiver to someone with a life-limiting illness who wishes to remain at home can be one of the ultimate gifts that one human can give to another. The government of Nova Scotia is supporting us with project funding for a Caregiver Tele-Connect initiative. Based on our successful Caregiver TeleGroup Support program, it aims to provide information, education, emotional support, and social connection for those giving palliative care.

In closing, although caregiving can be rewarding, it can also be challenging and demanding. My recommendations for a national dementia strategy would include the following.

Caregiver willingness, capacity and readiness to assume such roles should be assessed. Caregivers are also telling us that the healthcare community is increasingly expecting them to master complex medical procedures, from injections to wound care.

Reach out to caregivers to let them know that supports exist to assist them and to keep them healthy. We need to have contact with caregivers early in their journey. Research shows that they will be able to stay in their caregiving roles longer, which means their loved ones will be able to stay at home longer.

Respite care and adult day programs are crucial supports in dementia care. We recently worked with other organizations to provide three caregiver retreats in rural Nova Scotia. Two more are planned for this fall.

The Alzheimer Society’s First Link program is a good referral program by physicians after diagnosis. We also need to refer the caregiver separately to caregiving organizations. Additionally, when a patient or caregiver contacts home care for
services, the caregiver should be referred to a caregiving organization. A number of caregivers look after people who have other chronic health issues before their loved one is diagnosed with dementia.

Partnerships and collaboration among home care, caregiving organizations, and Alzheimer societies are essential to supporting the dyad of care recipient and caregiver.

In my province, as people call the Continuing Care department for home care services, referrals are also made to Caregivers Nova Scotia to ensure caregivers are aware of programs, services, and benefits available to them.

Caregivers play a critical role in the life of someone living with dementia. Thank you for giving me the opportunity to speak on their behalf.

Respectfully submitted,

Angus Campbell
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Caregivers Nova Scotia Association