



Circle of Care:

Supporting Family Caregivers in BC

A Policy Paper by BC's Doctors

October 2016



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Executive Summary

For many people suffering from debilitating health conditions, the majority of their day-to-day health care is provided not by a health care professional, but by a family member or friend.

Commonly referred to as “family caregivers,” these unpaid caregivers are an integral, yet often invisible, part of British Columbia’s health care system. Support from caregivers enables patients to remain at home for longer, which contributes to a higher quality of life for patients and their families.

As BC’s population becomes older, the prevalence of unpaid care is expected to grow. Although providing care to a friend or family member can be a fulfilling experience, it can also be extremely challenging – taxing caregivers physically, psychologically, and financially. According to the Office of the Seniors Advocate BC, close to one-third of caregivers caring for a chronically ill or disabled senior in BC are in distress. Left unaddressed, increasingly distressed caregivers contribute to poorer health outcomes for patients and for themselves, and to increasing demand on expensive hospital or long-term care services.

Physicians and government can play leading roles to support caregivers. At the local level, physicians are well-positioned to support caregivers and consider them as partners in care by including caregivers in patient care planning and implementation wherever appropriate. To support physicians, Doctors of BC commits to developing practical resources to help physicians engage with caregivers within their practice settings.

At the provincial level, Doctors of BC recommends that the BC Government formally recognize caregivers as a key partner in health care delivery and require the consideration of caregiver needs in health care and social service planning and provision.

In addition, Doctors of BC identifies other potential areas for enhanced caregiver support including access to respite care, patient/system navigation, and financial assistance programs. Doctors of BC is committed to working with government and other partners to develop and implement a health care approach that recognizes, includes, and supports caregivers as partners in care.

Doctors of BC Policy

Doctors of BC believes that physicians and government can play leading roles to support family caregivers and recommends a health care planning and delivery approach that recognizes, includes, and supports caregivers as partners in care.

To support this policy, Doctors of BC has identified the following commitments and recommendations.

Commitments

Doctors of BC commits to:

- a. Working with the BC Government and key stakeholders to develop a strategy to formally recognize caregivers as a key partner in health care delivery and to establish principles that require the consideration of caregiver needs in health and social service planning and provision.
- b. Developing practical resources to help physicians enhance supports for caregivers and to include caregivers as partners in care.
- c. Working with continuing medical education (CME) organizations to incorporate training in identifying, assessing, involving, and supporting caregivers in CME programs.
- d. Raising physician awareness of the role they can play in recognizing, including, and supporting caregivers.
- e. Raising physician awareness of available community resources that support caregivers.



Family caregivers are an integral, yet often invisible, part of British Columbia's health care system.

Recommendations

Doctors of BC recommends that:

- a. The BC Government, in collaboration with key stakeholders, develop a strategy to formally recognize caregivers as a key partner in health care delivery and establish principles to require the consideration of caregiver needs in health and social service planning and provision.
- b. The BC Ministry of Health consider the needs of caregivers in its development, implementation, and evaluation of enhanced home and community care programs/ models.
- c. The BC Ministry of Health enhance access to case managers for home care patients and applicants.
- d. The BC Ministry of Health consider patient navigator models to support:
 - i. Patients with mental illness and/or cognitive impairments
 - ii. Populations facing language, cultural, or socioeconomic barriers to accessing health care
- e. Further to the recommendation of the Canadian Medical Association (CMA), the Federal Government amend the Caregiver Amount and Family Caregiver Tax Credits to make them refundable.
- f. The BC and federal governments consider additional policy measures to address the financial challenges faced by caregivers.

Background

What is Family Caregiving?

For many people with chronic illness or disabilities, most of their care is provided by a family member or friend. Often referred to as “family caregivers” (referred to as “caregivers” from this point forward), these caregivers are vital to the daily delivery of health care services.

In this policy paper, caregivers are defined as individuals who take on an unpaid caring role for someone who requires assistance because of a physical or cognitive condition, an injury, or chronic life limiting illness.⁽¹⁾ Caregivers provide services that are essential to the day-to-day wellbeing of those they care for. Caregivers may provide emotional support and assistance with daily activities such as transportation, meal preparation, cleaning, personal care, medical treatments, scheduling appointments, and financial management.

The caregiver population is diverse as it includes families/friends caring for people across the life span from infants to seniors. Although Doctors of BC believes that all caregivers can benefit from greater recognition and improved supports, this policy paper will focus on caregivers providing care to adults.

Why Care About Caregivers?

According to the Health Council of Canada, unpaid caregivers provide between 70%-75% of care for people receiving home care in Canada.⁽²⁾ In monetary terms, one study conservatively estimates that the economic contribution of unpaid caregivers (age 45 and older) for the elderly is approximately \$26 billion per year in Canada.⁽³⁾

Support from caregivers enables patients to stay at home longer contributing to a higher quality of life for patients and, often, to greater peace of mind for their families.⁽²⁾ Also, by delaying or reducing the time patients spend in hospital or in long-term care, caregiver support may produce savings for the formal health care system.

However, caregiving responsibilities can be stressful. Caregivers may be more likely to suffer from physical and mental illness, social isolation, and financial distress. These burdens may precipitate caregiver burnout, leading to grief, increased use of health care services, higher mortality risk, and a decrease in quality of life for both caregiver and their care recipient.⁽²⁾

At the national level, the Canadian Medical Association (CMA) recognizes how the increased need for care of an aging population is contributing to greater caregiver burden. As such, the CMA is advocating for stronger support for caregivers from the federal government.⁽⁴⁾ Doctors of BC, in this paper, outlines its views and recommendations for how caregivers can be better supported at the provincial level in BC.

Policy Gap & Opportunity

Caregivers may suffer from increased physical, psychological, and financial strains that can reduce their ability to care for themselves and for their loved ones.

Physicians in BC can play a central role in advocating for and supporting caregivers. A health care approach that recognizes, includes, and supports caregivers can enhance patient care and improve health outcomes for both patients and their caregivers. As well, healthier and more capable caregivers can mitigate rising health care costs by reducing demand on expensive hospital or long-term care services.

Doctors of BC strives to advance the goal of the “Triple Aim”¹ to improve population health, enhance the experience of care, and reduce per capita cost. To meet these goals, Doctors of BC is committed to supporting caregivers.

Doctors of BC recognizes the broader policy question of whether the burden of care should fall on caregivers or on to the health system to increase supports. Although important, the answer to this question falls beyond the scope of this policy paper and the discussion herein is limited to how physicians and the health system can best support caregivers.

Who are Caregivers?

There is a strong possibility that, at some point in your life, you have provided or will provide care as a caregiver. Based on the 2012 General Social Survey, Statistics Canada estimates that in a given year eight million Canadians, including one million British Columbians, are actively providing care as a caregiver.²⁽⁵⁾ The most common conditions in Canada involving caregivers are cancer, cardiovascular disease, mental illness, and degenerative brain diseases (including Alzheimer’s).⁽⁵⁾

1 The Triple Aim is a framework developed by the Institute for Healthcare Improvement that describes an approach to optimizing health system performance.

2 The real scope of caregiving is likely greater than what statistics indicate. Studies suggest that the prevalence of caregiving is often underreported as many people do not characterize their own care activities as those of a caregiver.

KEY STATISTICS OF CAREGIVERS IN CANADA

- 54% of caregivers are female.
- 56% of caregivers are 45 years of age or above.
- 15% of caregivers are young caregivers between the ages of 15 to 24.
- 28% of caregivers are “sandwiched” between caregiving and childrearing.
- Caregivers 65 years of age or older are most likely to spend the longest hours providing care.
- 89% of caregivers provide care for one year or longer

Portrait of Caregivers 2012 – Statistics Canada

Growing Scale of Caregiving

In the future, the burden on caregivers is likely to grow given our aging population and the correlating increase of age-related chronic diseases. Today, just under one in four, or about one million British Columbians, are 65 years of age or older. By 2041, this demographic is projected to double to two million, or more than one in three British Columbians.⁽⁶⁾ Moreover, increasing life expectancies, declining birth rates, and an increase in non-traditional families will mean that caregiving responsibilities will become concentrated on fewer caregivers and persist for longer durations of time.⁽⁷⁾

The BC Ministry of Health’s policy framework emphasizes home and community care as a means for allowing patients to remain at home for as long as possible, avoiding emergency room visits, minimizing extended hospital stays, and delaying entry into long-term residential care.⁽⁸⁾ The health and well-being of caregivers is critical to health care delivery at home and in the community.

Burdens Faced by Caregivers

For many, caregiving can be a fulfilling experience that engenders feelings of closeness or intimacy between caregiver and care recipient. However, caregiving can be challenging and stressful. Many caregivers are thrust into caregiving roles suddenly due to illness or accident, and are thus ill-prepared for such responsibilities. In BC, home care assessment data suggests that close to one-third (29%) of caregivers caring for a chronically ill or disabled senior in BC are distressed.⁽⁹⁾ Broadly speaking, caregivers are often strained physically, psychologically, and financially.

A caregiver’s physical health can be adversely impacted by factors such as stress, lack of sleep, neglect of own health, or strenuous labour performed when providing care. For example, evidence suggests that stress from caregiving can have a detrimental effect on one’s immune system, blood pressure, and lipid profiles.⁽¹⁰⁾ Another study suggests that

caregivers may face increased mortality when compared to non-caregivers.⁽¹¹⁾ Physical wellbeing is of particular concern for senior caregivers who themselves are likely living with medical conditions.

Stress and anxiety can also be harmful to mental health. For example, research suggests that caregivers may be more likely than non-caregivers to suffer from anxiety, insomnia, and depression.⁽¹⁰⁾ These types of mental health stressors are exacerbated by social isolation. The time commitment and emotional toll of caregiving can separate a caregiver from their social networks. In this regard, young caregivers are of particular concern as they are more likely to be socially isolated, bullied, or perform poorly at school.⁽¹²⁾ Alarming, young caregivers may also be more likely to commit acts of self-harm.⁽¹³⁾

Financial burdens also warrant attention. Caregiving can be time consuming and may require the caregiver to reduce or forgo paid employment. As well, caregivers often pay out of pocket expenses for the purchase of goods, services, and transportation. One report estimates that approximately 35% of workers in Canada provide unpaid care while balancing job responsibilities.⁽¹⁴⁾ For caregivers who are employed, financial strain coupled with the commitment of caregiving may be associated with poorer physical and mental health, greater work-life conflict, increased absenteeism, lower job satisfaction, a higher number of visits to hospital, and reduced fertility.⁽¹⁵⁾

According to the Office of the Seniors Advocate BC (BC Seniors Advocate), the strongest predictors of increased caregiver distress in BC are the number of hours of care provided and caring for people with behavioral problems, significant cognitive impairments, or those experiencing depression.⁽⁹⁾

In rural and remote regions, demographic and geographic factors may exacerbate caregiver burden. On average, rural residents tend to be older, less formally educated, and of lower income relative to urban populations. Moreover, rural individuals face challenges such as limited access to health services, transportation over long distances, and less family support.³⁽¹⁶⁾

Some groups, such as aboriginal, ethnic, and LGBTQ⁴ communities face further challenges that may exacerbate caregiver burden. These communities may face socio-demographic, cultural, linguistic, economic, and structural barriers to accessing health care services.^(8, 17) For example, the lack of trust many aboriginal people have in the health care system translates into lower utilization of health services by aboriginals relative to non-aboriginal people.⁽¹⁸⁾

3 In remote/rural regions, it is common for younger adults to move away to larger urban centres, reducing their ability to provide care to their aging parents.

4 LGBTQ is the acronym for lesbian, gay, bisexual, transgendered & queer.

Policy Opportunities

Recognizing Caregivers as Partners in Health Care Delivery

Canada's aging population and the rising importance of home and community health care has highlighted the central role that caregivers play in health care delivery. In the 2002 report, *Building on Values – The Future of Health Care in Canada*, Commissioner Roy Romanow stated that “home care could not exist in Canada without the support of social networks and informal caregivers.”⁽¹⁹⁾ In 2009, the Special Senate Committee on Aging advocated, among other measures, for the creation of a National Caregiver Strategy to address the needs of caregivers in a comprehensive and multi-jurisdictional manner.⁽²⁰⁾

International jurisdictions, such as the UK and Australia, have taken such national approaches. In 2008, the UK Government announced a national carer⁵ strategy, subsequently revised in 2014 as the *Carer Strategy – Second National Action Plan 2014-2016*.⁽²¹⁾ In 2010, the Australian Government enacted the *Carer Recognition Act* and in 2012 published the *National Carer Strategy Action Plan 2011-2014*.⁽²²⁾ Both jurisdictions have legislation recognizing the role of caregivers and commit to supporting caregivers by establishing key priorities for government action. Common priorities include:

- Identifying and recognizing caregivers
- Involving caregivers in the planning and delivery of patient care
- Enhancing economic security of caregivers
- Improving the quality of health services for caregivers
- Enhancing health and well-being of caregivers
- Providing better training and education to caregivers

Few provinces in Canada have taken such a legislative or planning approach. In 2011, the Manitoba Government enacted the *Caregiver Recognition Act*, which established principles relating to caregivers and outlined how caregivers should be treated and considered by the public, health care staff, and the workplace.⁽²³⁾

In BC, caregivers are included in Ministry of Health policy. In 2014, the Ministry of Health released a set of policy papers outlining its priorities for health system improvement. Specifically, the Ministry of Health identifies caregivers and families as partners in health care and as a key component of patient-centred care.⁽²⁴⁾ This is a positive step toward stronger recognition for caregivers and can be further strengthened through formal recognition by the provincial government.

⁵ In the UK and in Australia “caregivers” are referred to as “carers”.

At the practice level, client assessments and care planning carried out by home and community care professionals include an assessment of caregiver status and needs.⁽²⁵⁾ At this level, there may be opportunities for Doctors of BC to work collaboratively with health authorities and the Ministry of Health to enhance the use of caregiver assessment data to improve patient care planning.

DOCTORS OF BC RECOMMENDS THAT:

- *The BC Government, in collaboration with key stakeholders, develop a strategy to formally recognize caregivers as a key partner in health care delivery and establish principles to require the consideration of caregiver needs in health and social service planning and provision.*

DOCTORS OF BC COMMITS TO:

- *Working with the BC Government and key stakeholders to develop a strategy to formally recognize caregivers as a key partner in health care delivery and establish principles to require the consideration of caregiver needs in health and social service planning and provision.*

CAREGIVER LEGISLATION & COMMITMENTS - UNITED KINGDOM

In the UK, a national caregiver strategy has been accompanied by legislation and National Health Service (NHS) commitments to support caregivers. In England, the *Care Act 2014* gives adult caregivers caring for another adult the same legal right to assessments and supports as care recipients.⁶⁽²⁶⁾ Previous to the *Care Act*, caregivers did not have the legal right to receive support, which gave local governing authorities discretion over the provision of services to caregivers. This contributed to varied and inconsistent access to support services for caregivers across the country.

In 2014, NHS England outlined a set of commitments to caregivers that focus on priority areas including raising the profile of caregivers, education and training, service development, person-centred care, primary care, research and evaluation, partnerships, and NHS England as an employer. Progress on each commitment is monitored and annually reported by NHS England.⁽²⁷⁾

How Can Physicians Support Caregivers?

The patient-physician relationship has traditionally focused on the patient, with less attention being paid to the patient's caregiver. In some cases, the caregiver has become an "invisible patient" potentially suffering from their own physical and psychological conditions.⁽²⁸⁾

As care providers for people with chronic illness and disabilities, physicians are well positioned to support caregivers. In maintaining a patient focus but also acknowledging and including the caregiver, physicians can have a positive impact on the caregiving experience. For instance, studies indicate that caregivers experience less depression when physicians take the time to listen and attend to their needs and opinions.⁽²⁹⁾

6 The Care Act is in England only. Wales and Scotland have similar legislation such as the Social Services and Wellbeing Act 2014 and the Social Care (Self-directed Support) Act 2013 respectively. England's Care Act does not deal with assessment of caregivers under the age of 18 or parent caregivers, however, the Children and Families Act 2014 gives young caregivers and parent caregivers (in England) similar rights to assessment as caregivers under the Care Act.

Moreover, physicians recognizing caregivers as partners in care can positively influence patient care planning and implementation. First, caregivers possess knowledge about care recipients that can inform patient care planning and help physicians identify problems that may require intervention. Second, the cooperation of caregivers is often required to effectively implement a patient care plan.⁽³⁰⁾

For example, a physician initiating advance care planning discussions should include a patient's caregivers as much as possible to facilitate optimal end-of-life care, sound financial/legal planning, and clear decision-making processes.⁷

Doctors of BC is committed to developing practical resources to help physicians include caregivers as partners in care and to enhance physician supports for caregivers. Specifically, physicians and their practices can take concrete actions to:

1. Identify caregivers
2. Involve caregivers in patient care
3. Monitor the health of caregivers
4. Provide information and support to caregivers

First, caregivers need to be identified before they can be supported. Ideally, physicians will have the resources to identify primary and secondary caregivers, understand their responsibilities, and acknowledge their work whenever possible.⁽³¹⁾ At this stage, important questions may include:

1. Who is the person providing the most care to the patient and, if the patient is unable to, makes the medical, financial, and legal decisions? (the primary caregiver)
2. Who else is available to assist with the care of the patient? (the secondary caregivers)
3. What are the capabilities and current responsibilities of each caregiver?

⁷ For more information on the Doctors of BC's position on advance care planning, please see policy paper *It's Time to Talk: Advance Care Planning in British Columbia*.

Second, physicians can consider including caregivers as partners in patient care. In practice, where appropriate, physicians can seek permission from patients to share relevant information with caregivers and seek input from caregivers in patient care planning and implementation.

Third, physicians can determine the caregivers' emotional and ongoing support needs. A physician may do this informally by asking caregivers about their physical/mental health or about the amount of time spent caregiving. Formal caregiver stress assessment tools can also be used to assess the needs of caregivers. Many caregiver stress assessment tools can be administered by non-clinical staff or completed by the caregivers themselves. Ideally, an assessment of a caregiver's needs occurs periodically, particularly when there is a change in the condition of the patient or caregiver or when the patient is transitioning to a new care setting.⁽³²⁾ Examples of validated assessment tools include the Zarit Burden Interview, Modified Caregiver Strain Index, and Caregiver Self-Assessment Questionnaire. As an example, Appendix A provides a copy of the Zarit Burden Interview.

And fourth, once a caregiver's needs are assessed, the physician is better positioned to help a caregiver access necessary supports. In some cases, a physician may refer patients and caregivers to appropriate home and community care services. Additionally, physicians may refer caregivers to suitable community support resources. For example, the Family Caregivers of British Columbia (FCBC), in partnership with the BC Ministry of Health, provides BC residents with services such as the Caregiver Support Line (via telephone), education for caregivers and health professionals, and an online caregiver resource centre. In addition, BC's First Nations Health Authority manages the delivery of a range of health services and programs intended to support health and wellness in First Nations communities. For more information on suggested resources for caregivers in BC, please see Appendix B.

It is important to note that physicians looking to include caregivers in patient care may face challenges. Physicians may have limited knowledge or confidence in caregiver support services in the community, they must balance the need to involve the caregiver with the need to safeguard patient privacy, or they may be placed in the position of navigating disagreements between caregiver and patient. As well, a physician's relationship with a caregiver may be further complicated if the caregiver is attached to a different physician.

Physicians may also need to manage cultural or linguistic differences between themselves and their patients/caregivers. Cultural safety training programs, such as the San'yas Indigenous Cultural Safety Training Program delivered by the Provincial Health Services Authority (PHSA), are available to physicians.⁽³³⁾ The PHSA also provides interpreting and translation services to health care providers working within a BC health authority.⁽³⁴⁾



Physicians recognizing caregivers as partners in care can positively influence patient care planning and implementation.

It should be noted, where physicians are prepared to offer supports for caregivers, current compensation models may not fully contemplate the additional time and resources required.

As well, physicians may not be the sole providers of patient care. Where possible, physicians should engage with other health care professionals, such as nurses and social workers, to provide additional assistance to patients and their caregivers.⁸

DOCTORS OF BC COMMITS TO:

- *Developing practical resources to help physicians enhance supports for caregivers and include caregivers as partners in care.*
- *Working with continuing medical education (CME) organizations to incorporate training in identifying, assessing, involving, and supporting caregivers in CME programs.*
- *Raising physician awareness of the role they can play in recognizing, including, and supporting caregivers.*
- *Raising physician awareness of available community resources that support caregivers.*

Respite Care

Respite care is temporary care of a dependent, elderly, ill, or handicapped person, that provides relief for their usual caregivers. Studies indicate that caregiving intensity is a significant risk factor for caregiver distress.^(9, 28) As mentioned earlier, it is estimated that close to one-third of caregivers caring for a chronically ill or disabled senior in BC are distressed. Distressed caregivers provide, on average, 30 hours of care per week to care recipients.⁽⁹⁾ Respite care can reduce caregiver stress by providing caregivers with a break from their caregiving duties to leave the home, re-charge, or access information and resources.

BC has three main types of government subsidized respite for caregivers caring for seniors:

1. In-Home Respite
2. Adult Day Programs
3. Respite Beds (Short-term Residential Care)

⁸ For more information on Doctors of BC's position on multidisciplinary care, please see Doctors of BC's policy statement titled *Multidisciplinary Primary Care*.

In-Home Respite

In-home respite is offered through home support services which are direct care services provided by community health workers to clients in the home. Research indicates that home support services can be an effective form of preventive health care by helping to monitor health status, avert health crises, and delay the need for institutional care.⁽³⁵⁾

Since the mid-1990s, home support in BC has become more focused on post-acute care and less on prevention and maintenance. This shift is illustrated by reductions in the provision of non-personal services, such as housekeeping, meal preparation, social support, and shopping.⁹⁽³⁶⁾

Access to home support services in BC may also be increasingly limited. Although BC's population has become older, the number of clients receiving home support in 2013-2014 was the same as the number of clients receiving home support services in 2001-2002.⁽³⁵⁾

Adult Day Programs

Adult Day Programs (ADP) are delivered at community locations and provide services ranging from personal care, recreational activities, health education and promotion, nursing and rehabilitation, and caregiver support.⁽³⁷⁾

Access to ADP services may be increasingly limited. According to the BC Seniors Advocate, ADP capacity has not kept pace with the growth of BC's aging population, as evidenced by a drop in ADP clients and ADP days utilized even as the senior population has grown in recent years.⁽⁹⁾

Respite Beds (Short-Term Residential Care)

Respite beds allow seniors to leave home and stay in a residential care facility for up to 30 days in a one year period. A typical residential care facility may allocate a small percentage of total beds to short-term respite care and may decrease the number of short-term beds if additional beds are needed to provide long-term residential care.⁽⁹⁾

Similar to other types of respite care, access to respite beds may be limited. Based on home care assessment data, the BC Seniors Advocate identified a significant gap between seniors who can potentially benefit from respite and the actual number of seniors using respite beds. Moreover, from 2012-2015, although the number of seniors accessing respite beds increased, the average length of stay per senior decreased. The declining length of average stay is worrisome because the effectiveness of a respite bed as relief for the caregiver is linked to the length of time the caregiver is relieved.⁽⁹⁾

9 Some assistance with daily tasks is provided by the Better at Home Program. Funded by the BC Government and managed by United Way of the Lower Mainland, the program provides services to assist seniors with tasks such as grocery shopping, housework, and transportation. These services may be provided by volunteers, contractors, or paid staff.

More Resources Needed for Home & Community Care

In BC, limited access to respite services may be a symptom of an under-resourced home and community care system. Since 2008, Doctors of BC has advocated for increased funding for home and community care programs in BC. For more information on the Doctors of BC's position on BC's home and community care system, please see policy paper *Bridging the Islands: Re-building BC's Home & Community Care System*.

DOCTORS OF BC RECOMMENDS THAT:

- *The BC Ministry of Health consider the needs of caregivers in its development, implementation, and evaluation of enhanced home and community care programs/models.*

Helping Patients & Caregivers Navigate Health Care System

An important role for many caregivers is to help care recipients navigate the health care system. Caregiver responsibilities may include accessing information on health programs, coordinating health appointments, applying for financial support, and advocating for care recipient or family. For many caregivers, navigating the complex health care system is among the most stressful aspects of caregiving.⁽¹⁵⁾ This burden is further exacerbated for aboriginal and ethnic populations that face additional language, cultural, or socioeconomic barriers to accessing health care.

Over the long-term, home and community care models should be designed to reduce system complexity. Encouragingly, the BC Ministry of Health is emphasizing the need for simplified patient pathways and stronger linkages between primary care and specialized services in its approach to improving health care delivery across the province.⁽⁸⁾ These efforts are positive steps toward a more simplified health care system for patients, caregivers, and health care providers.

In the meantime, to the degree possible, primary care physicians can help patients and their caregivers navigate the health care system through appropriate referrals or by providing information on available resources. For many patients with complex health needs and/or who face other barriers to accessing health care, on-going support with system navigation is required. Ongoing assistance to patients and caregivers in BC can be provided by case managers or patient navigators.

A patient accessing home and community care services is typically assigned a case manager. This case manager is responsible for working with the patient, caregivers, physicians, and other health care professionals to assess patient needs, develop a care plan, and coordinate health services. Unfortunately, a heavy caseload is a challenge for many case managers. In BC, case managers report that large caseloads lead to long wait-times for people attempting to access care and less in-depth case management for people receiving care.⁽³⁸⁾

Another model for system navigation involves the use of patient navigators. Patient navigators may act as patient advocates and help patients and caregivers connect with specialists, coordinate care services, and obtain financial support. A patient navigator may be a health care professional, a social worker, or a volunteer.

Examples of patient navigator programs in BC are the Aboriginal Patient Navigator/Liaison programs offered by regional health authorities.⁽³⁹⁾ Additionally, other patient navigator programs in BC may be provided by disease-specific organizations and/or local Divisions of Family Practice.⁽⁴⁰⁻⁴²⁾

DOCTORS OF BC RECOMMENDS THAT:

- *The BC Ministry of Health enhance access to case managers for home care patients and applicants.*
- *The BC Ministry of Health consider patient navigator models to support:*
 - *Patients with mental illness and/or cognitive impairments*
 - *Populations facing language, cultural, or socioeconomic barriers to accessing health care*

PATIENT NAVIGATOR PROGRAM – SUNSHINE COAST DIVISION OF FAMILY PRACTICE ⁽⁴²⁾

Susan is a caregiver to her spouse who has terminal cancer and a mother of young children. Under stress, Susan quit her job to provide care for her family. Susan's family doctor recognized signs of caregiver burnout and referred Susan to the Sunshine Coast's Patient Navigator Program.

The Patient Navigator met Susan in her home and spoke with her about the physical and mental strain of Susan's caring responsibilities. Additionally, the Patient Navigator recommended and helped Susan apply for income assistance and worked with Susan's family doctor to connect Susan to appropriate social services.

Beginning in April 2015, a Patient Navigator (social worker) has been helping vulnerable patients and their caregivers in BC's Sunshine Coast connect to social services and health care systems. Individuals are referred to the Patient Navigator through sources such as physicians, the emergency room, RCMP, Vancouver Coastal Health, community organizations, and family or friends.

From April to August 2015, more than 150 patients were referred to the Patient Navigator. The most common services provided by the Patient Navigator are information and support, advocacy, referral, and GP attachment.

Reducing Financial Strains

Caregivers can suffer financial distress from out-of-pocket expenses and from reducing or forgoing paid work. Financial strains lead to increased stress and can further exacerbate mental and physical health conditions.

Financial supports for caregivers in BC are limited. The Federal Government offers financial assistance through Employment Insurance and non-refundable¹⁰ tax credits. Provincial legislation in BC also provides caregivers who are employed with some measure of job protection.

Caregivers in Canada who must leave the workplace to provide end-of-life care for a family member¹¹ can access Compassionate Care Benefits (CCB) from Employment Insurance.⁽⁴³⁾ As for tax credits, caregivers may be eligible to claim credits, such as the Caregiver Amount, Family Caregiver Tax Credit, and/or the Disability Tax Credit.^(44, 45) A summary of financial benefits and associated application details is provided in Appendix C.

In terms of job protection, BC's Employment Standards Act (ESA) complements the CCB by requiring employers to provide up to eight weeks of unpaid leave to an employee who must leave the workplace to provide end-of-life care to a family member. In addition, the ESA requires employers to provide employees with up to five days of unpaid leave to care for an immediate family member.¹²⁽⁴⁶⁾

A number of jurisdictions can offer BC additional ideas on providing financial assistance to caregivers. For example, the Manitoba Government provides caregivers with a refundable¹³ Primary Caregiver Tax Credit.⁽⁴⁷⁾ Quebec provides a number of refundable tax credits for caregivers and for the use of respite services.⁽⁴⁸⁾

In Nova Scotia, caregivers may be eligible for direct monthly payments through the Caregiver Allowance program.⁽⁴⁹⁾ This type of direct payment to caregivers also exists in international jurisdictions, such as Australia and the UK, where national governments provide a number of weekly, annual, and one-time payments to assist caregivers in various circumstances.^(50, 51)

10 The value of "non-refundable" tax credits cannot exceed the amount of tax owed by an individual. This means that, for example, low income individuals who pay little or no taxes cannot receive a tax refund if the value of non-refundable tax credits exceeds the amount of tax they owe.

11 Definition of "family member" is broad and includes close friends (no blood relation) with a serious medical condition.

12 Note that employers may offer services/arrangements that go beyond the leave provisions required by the ESA, such as employee support programs, flexible work hours, teleworking, or paid/unpaid leave.

13 The value of "refundable" tax credits can exceed the amount of tax owed by an individual. Low income individuals who pay little or no taxes may receive a tax refund if the value of refundable tax credits exceeds the amount of tax they owe.

In the United States, the majority of states administer variations of Cash and Counseling Programs which provide Medicaid patients with “consumer-directed” personal care budgets. Eligible program participants manage a flexible budget and can decide the mix of goods and services that best meet their personal care needs.⁽⁵²⁾ This includes the flexibility to hire family and friends as caregivers. In BC, health authorities provide similar self-managed home support programs called Choice in Supports for Independent Living (CSIL). However, CSIL participants are typically not permitted to hire immediate family members as caregivers.¹⁴⁽⁵³⁾

DOCTORS OF BC RECOMMENDS THAT:

- *Further to the recommendation of the CMA, the Federal Government amend the Caregiver Amount and Family Caregiver Tax Credits to make them refundable.(54)*
- *The BC and Federal Governments consider additional policy measures to address the financial challenges faced by caregivers.*

¹⁴ In certain circumstances (cultural barriers, unique care needs, rural or remote location), temporary exceptions to hire immediate family member may be applied for and granted by a case manager.

Conclusion

Doctors of BC is committed to supporting physicians and working with government and other partners to develop and implement a health care approach that recognizes, includes, and supports caregivers as partners in care. As an initial step, Doctors of BC commits to developing practical resources to help physicians engage caregivers within their practice settings.

As the population ages, more British Columbians will be providing unpaid care. Caregivers who are healthier, recognized for their contributions, and included in patient care can positively impact health outcomes and help prevent or delay hospitalizations.

Physicians are well positioned to support caregivers and their loved ones. Through strong advocacy and the inclusion of caregivers as partners in patient care, physicians can make a meaningful difference in the health and well-being of patients, families, and communities.



Caregivers who are healthier, recognized for their contribution, and included in patient care can positively impact health outcomes and help prevent or delay hospitalization.

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Appendix A:

Zarit Burden Interview (Short Version)⁽⁵⁵⁾

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	Score
1. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4	
2. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4	
3. Do you feel angry when you are around your relative?	0	1	2	3	4	
4. Do you feel that your relative currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4	
5. Do you feel strained when you are around your relative?	0	1	2	3	4	
6. Do you feel that your health has suffered because of your involvement with your relative?	0	1	2	3	4	

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	Score
7. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4	
8. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	
9. Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4	
10. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
11. Do you feel that you should be doing more for your relative?	0	1	2	3	4	
12. Do you feel that you could do a better job in caring for your relative?	0	1	2	3	4	
					Total Score (Max = 48)	

Appendix B: Community Resources for Caregivers in BC

Family Caregivers of British Columbia (FCBC) www.familycaregiversbc.ca

- **Caregiver Support Line** (1-877-520-3267) - Monday to Friday, 8:30am to 4pm PST
 - One on one phone support
 - Information and referral to community resources
 - Assistance in health care system navigation
 - Caregiving coaching appointments for emotional support, problem solving and brief action planning
- **Education for caregivers and health professionals**
 - Tele-workshops (phone only) and/or webinars on topics relating to caregiving
 - Family Caregiver Support Group Facilitator training for volunteers or staff to effectively set up and run support groups in your community.
- **Online Caregiver Resource Centre**
 - Listing and contact information for caregiver support groups in BC.
 - Resource Guide for Family Caregivers, 2nd Edition
 - Toolkit for Employers: Resources for Supporting Family Caregivers to provide employers and employees with information and resources to help minimize the impact of caregiving on both employee and the workplace.

Family & Friend Caregivers Information and Resource Handbook (United Way of the Lower Mainland)

www.uwlm.ca/resources/caregivers-information-and-resources-handbook/

The handbook provides information to assist family or friend caregivers of the elderly and covers topics including health care, housing, and law.

Better at Home Program www.betterathome.ca

Better at Home is a program that helps seniors with day-to-day tasks so they can continue to live independently in their homes and remain connected with their communities. Funded by the Government of British Columbia, the program is managed by the United Way of the Lower Mainland and services are provided by local non-profit organizations. Seniors living in a community that offers Better at Home can contact a local organization to find more information and to apply for services.

HealthLink BC www.healthlinkbc.ca

Call 811 (711 for the hearing impaired) from anywhere in BC to speak with a nurse (24/7), dietitian (Monday to Friday, 9am to 5pm) or a pharmacist (Monday to Sunday, 5pm to 9am). Translation services are available.

Medically approved information on various health topics, symptoms, medications, and tips for maintaining a healthy lifestyle can be found on the HealthLinkBC website.

bc211 www.bc211.ca

bc211 (24 hours a day & 365 days a year) is a Lower Mainland based organization that specializes in providing information and referral regarding community, government, and social services in the Fraser Valley, Metro Vancouver, Squamish-Lillooet, and the Sunshine Coast. bc211 can also be contacted via text message from 8am-11pm (365 days a year). bc211 is expected to begin serving all of BC by the end of 2016.

BC Bereavement Helpline (BCBH) www.bcbereavementhelpline.com

Call the BCBH at 1-877-779-2223 for a free and confidential service that connects individuals to grief support services in BC.

First Nations Health Authority (FNHA) www.fnha.ca

The FNHA plans, designs, manages, and funds the delivery of First Nations health programs and services in BC. These community-based services are largely focused on health promotion and disease prevention.

Provincial Language Service - Provincial Health Services Authority (PHSA)

<http://www.phsa.ca/our-services/programs-services/provincial-language-service>

The Provincial Language Service provides interpreting and translation services to BC health authorities. Please see website for more information about booking an interpreter or requesting a translation.

Alzheimer Society of British Columbia www.alzheimer.ca/bc

• **First Link® Dementia Helpline**

- People who are living with dementia or who have questions about the disease can call the First Link Dementia Helpline Monday to Friday, 9am to 4pm at (toll free) 1-800-936-6033 or (Lower Mainland) 604-681-8651.

• **First Link® Formal Referrals**

- First Link® Formal Referrals help physicians and other health care providers connect individuals and their care partners to Society services and support. Health care providers can visit the Society's website for details on how to make a referral.

Other Society programs include education workshops, support groups and fitness/social programs.

Canadian Virtual Hospice www.virtualhospice.ca

The Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers, and educators.

Appendix C: Financial Benefits for Caregivers

	Compassionate Care Benefits - Employment Insurance ⁽⁴³⁾	Non-Refundable Family Caregiver Tax Credit (Canada) ⁽⁴⁴⁾	Non-Refundable Disability Tax Credit (Canada) ⁽⁴⁵⁾
Who is eligible?	Individuals who must be absent from work to provide care or support to a family member ¹⁵ at a significant risk of dying within 26 weeks may be eligible.	Individuals who have a dependent with an impairment in physical and mental functions may be eligible.	Individuals who have a severe and prolonged impairment may be eligible.
How to apply?	Applicants can apply online at Service Canada website or at a Service Canada Centre location.	Tax credit can be claimed on an individual's tax return.	Applicant (or legal representative) and medical practitioner must complete Form T2201, Disability Tax Credit Certificate. Applicant can send completed Form T2201 directly (no 3rd party intermediary required) to the Disability Tax Credit Unit of a tax centre. If application is approved by the CRA, the disability amount on tax return can be claimed.
What benefits are available?	Weekly payments provided for a maximum of 26 weeks (+ 2 week waiting period)	Additional tax credit for one or more of the following amounts: Spouse or common law partner amount; amount for an eligible dependent; and caregiver amount.	Individuals eligible for the Disability Tax Credit may claim the disability amount on their tax return.

¹⁵ "Family member" may include a gravely ill person who considers their caregiver as a family member, such as a close friend or neighbour.

	Compassionate Care Benefits - Employment Insurance ⁽⁴³⁾	Non-Refundable Family Caregiver Tax Credit (Canada) ⁽⁴⁴⁾	Non-Refundable Disability Tax Credit (Canada) ⁽⁴⁵⁾
What documents or medical proof are required?	<p>Form INS5216A - Authorization to Release Medical Certificate, which must be signed by the gravely ill person or their legal representative and;</p> <p>Form INS5216B - Medical Certificate for Employment Insurance Compassionate Care Benefits, which must be completed and signed by the medical doctor of the gravely ill person to confirm significant risk of death within 26 weeks.</p>	<p>The Canada Revenue Agency may ask for a signed statement from a medical practitioner showing when the impairment began and what duration of the impairment is expected to be.</p> <p>For children under 18 years of age, the statement should also show that the child, because of an impairment in physical or mental functions, is and will continue to be dependent on others for an indefinite duration. This dependence means they need much more assistance for their personal needs and care compared to children of the same age.</p> <p>You do not need a signed statement from a medical practitioner if the CRA already has an approved Form T2201, Disability Tax Credit Certificate, for the specified period.</p>	<p>Medical practitioner must complete Part B of the Form T2201. More information for medical practitioners can be found http://www.cra-arc.gc.ca/arc.gc.ca/dtcmedicalpractitioners/</p>
Need more information?	www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml	www.cra-arc.gc.ca/familycaregiver	http://www.cra-arc.gc.ca/dtc/

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