



AN INTEGRATED PALLIATIVE APPROACH TO CARE • DES SOINS QUI INTÈGRENT L'APPROCHE PALLIATIVE



VALUING CAREGIVING AND CAREGIVERS: FAMILY CAREGIVERS IN THE INTEGRATED APPROACH TO PALLIATIVE CARE

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Quality End-of-Life
Care Coalition of Canada
La Coalition pour des soins
de fin de vie de qualité du Canada



Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs



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We are grateful to all the reviewers for their valuable contributions to review, evaluate and comment on this discussion document, including:

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Doug Kellough, Canadian Association for Spiritual Care
Tanny Nadon, Canadian Cancer Action Network
Marlene Chatterson, Canadian Association of Social Workers
Shirley DeMerchant, Women's Inter-Church Council of Canada
Shelly Cory, Canadian Virtual Hospice

Production of this document has been made possible through a financial contribution from the Government of Canada.

The views expressed herein do not necessarily represent the views of the Government of Canada.

For citation: Canadian Hospice Palliative Care Association, *Valuing Caregiving and Caregivers: Family Caregivers in the Integrated Approach to Palliative Care*, The Way Forward initiative: an Integrated Palliative Approach to Care, 2013.



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EXECUTIVE SUMMARY

Family caregivers are fundamental to health care in all settings in Canada.

Family caregivers (referred to simply as “caregivers” in this document) are family members, friends and neighbours. They provide care and assistance for spouses, children, parents and other extended family members and friends who are in need of support because of age, disabling medical conditions, chronic injury, long term illness or disability. With the aging population, the number of individuals actively caring for a friend or family member is expected to increase.

Typically caregivers welcome the opportunity to provide care and support to a loved one, whether at home or in a hospital or long-term care facility. However, caregiving has a profound effect — emotionally, mentally and physically — on caregivers. Providing care at the end of life can compound the impact {Addington-Hall & Karlsen, 2000; Stajduhar & Davies, 2005} — yet very few families formally plan for this responsibility.

On average, Canadians estimate that they would have to spend 54 hours per week to care for a dying loved one at home {Ipsos-Reid Survey, 2004}, and two-thirds say they could not devote the time needed for this care. {Ipsos-Reid Survey, 2004} If we are to care for the growing number of Canadians who will die over the next 40 years, we must acknowledge the importance of family caregiving and make it a social value. There is still much work to be done by the health system to adequately support individuals with chronic life-limiting illnesses and their families through to end of life.

The health system is more effective, and care for people who are dying is better, when an integrated palliative approach to care is available in all settings — acute care, long-term care and at home — and when caregivers have the support they need to reduce the emotional, physical, psychosocial and financial stresses associated with caring for a family member in all care settings.

Integrating hospice palliative care services across the health care system is critical to ensuring that:

1. Pain and symptom control, psychosocial distress, spiritual issues and practical needs are addressed with the patient and family throughout the continuum of care;
2. The caregiver is acknowledged for his or her contribution and provided with consistent information, education and training;

3. Care is patient-centred and respects the individual's values, goals, and role in decision-making regarding his or her plan of care;
4. Communication between providers at transition points in care, or settings of care, minimizes variation and inconsistency. {Collins, Jones, Peres, & Spragens, 2008}

As our society becomes more aware of the importance of family caregiving at end-of-life, all sectors of society must openly demonstrate an interest and commitment to supporting caregivers. The health care system should provide appropriate supports and employers should respond to employees' needs by offering flexibility at work, information and assistance, and emotional and other supports. Governments should establish the right balance of responsible fiscal and social policy to support and empower caregivers, using levers such as tax measures, financial support programs, and labour code modifications. There should be more public discussion about death and dying, and the importance of high quality end-of-life care.

Caregivers are essential at end-of-life. Canadians need to actively and openly commit to supporting family caregiving.

INTRODUCTION

Canadians are defined by a culture of caring. When a loved one needs care, we assume and expect that families and/or friends will be there to provide support.

However, social and economic changes are threatening those expectations. Families are smaller and more dispersed so there are fewer family members to share the care. Women are the traditional caregivers but, with more women working in the formal workforce, marrying and having children later in life and retiring later, they are less able to provide that care.

At a time when there is a decreasing supply of caregivers, care demands are increasing. Although Canadians are living longer, they are more likely to have one or more disabilities, which complicates their care. In the past, the time from diagnosis to death was relatively short, and the demands on caregivers — while intense — were also relatively short. Now, many individuals, particularly the elderly, will live many years with a life-limiting illness and experience a slower decline in health — placing more demands on a smaller number of caregivers.

Both professional and family caregivers will be challenged to meet the needs of aging Canadians for hospice palliative care services. We need an integrated approach that gives individuals and families access to key hospice palliative care services and supports earlier in the course of the illness and throughout the trajectory of the disease. The health system — and all sectors of society — must retool to respond to the needs of our aging population. We must acknowledge the importance of planning for the end of life and creating a societal construct that recognizes and values the role that caregivers will play in the care of the elderly.

This paper explores the challenges that caregivers face as well as potential opportunities to support them, including the roles of the health system, employers, governments and communities. There is no single solution: all Canadians need to make a commitment to family caregiving as an unquestionable social value and demonstrate that commitment through comprehensive meaningful support for caregivers.



THINKING DIFFERENTLY ABOUT CARE AT THE END OF LIFE

Death is not an option. How one dies is.

One-hundred-percent of people in Canada will die. For most, death will occur in old age. Most Canadians still die in hospital {Statistics Canada, 2008}, but a growing number are now dying at home {Canadian Institute for Health Information, 2007} and in long-term care homes. {Wilson, Truman, Thomas, et al, 2009} Some die in other settings, such as hospices, shelters, prisons or group homes. Approximately 10 percent of people die suddenly {Plonk & Arnold, 2005; Statistics Canada, 2012}; the other 90% would benefit from end of life care. {Carstairs, 2010}

Hospice palliative care is a philosophy of care that aims to relieve suffering and improve the quality of living and dying.

Historically, hospice palliative care has been the care provided at end of life — after curative treatments have stopped. In 2002, after ten years of consultation, the CHPCA, in collaboration with other stakeholders,

developed national principles and norms of practice for hospice palliative care. This seminal work shifted the approach from “care for the dying,” to “care that aims to relieve suffering and improve quality of life throughout the illness and bereavement experience, so that patients and families can realize their full potential to live even when they are dying”. {Canadian Hospice Palliative Care Association, 2002}

The aging of Canada’s population is driving the growing interest in the integrated palliative approach to care. From 2006 to 2007, there were 233,825 reported deaths in Canada. {Statistics Canada, 2011} By 2056, the number of deaths each year will double to almost 480,000. {Statistics Canada}

In the past decade health regions across the country have implemented hospice palliative care programs to support end-of-life care. Because a cancer diagnosis was often a predictor of death with a clearly defined terminal phase, hospice palliative care has focused mainly on those with cancer. {Canadian Hospice Palliative Care Association, unpublished} The needs of Canadians dying

with other illnesses that have less predictable trajectories, such as organ failure and frailty, remain largely overlooked. As a result, at least 70% of Canadians do not have access to hospice palliative care services. {Carstairs, 2010}

THE OPPORTUNITY: ENHANCING CARE FOR PEOPLE WITH CHRONIC LIFE-LIMITING CONDITIONS

“There is only one chance to support an individual at the end-of-life. We have to get it right.”

The number of chronic conditions determines how often seniors consult physicians and use medications, and having chronic conditions increases the likelihood of being hospitalized and receiving home care. {Rotermann, 2006}

Life expectancy at birth for Canadians is now 79 for men and 83 for women. {Statistics Canada, 2012} Today, seniors are typically healthier and more independent longer in life. However, as they age, many will develop chronic conditions that will affect their health over many months or years. About 41% of

Canadian seniors have two or more chronic conditions, such as diabetes, respiratory issues, heart disease, and depression, and many are experiencing a decline in physical and/or cognitive functioning. {Health Council of Canada, 2010}

A growing number of practitioners believe there is an opportunity to provide more people in Canada, particularly those with a non-cancer diagnosis, with palliative care support integrated with their ongoing treatment. While people plan to live, they also prepare for the fact that they will one day die from their illness.

The Canadian Hospice Palliative Care Association (CHPCA) believes that hospice palliative care is an integral component of professional practice and should be available for all Canadians regardless of their specific illness or their setting of care. The CHPCA is advocating for an integrated palliative approach to care: one that would ensure seamless access to palliative services in all settings where people receive care for chronic, life-limiting conditions including acute care, complex continuing care, long term care, home care and primary care. This integrated palliative approach to care would be provided by primary care, home care, long-term care and acute care teams with support, as required, from community and hospital-based palliative care specialist consult teams and hospices. As a key member of the care team, the family caregiver plays a role in this integrated care in all settings.

THE ROLE OF CAREGIVERS AND THE IMPACT OF CAREGIVING

The way individuals who are dying are cared for and their family caregivers are recognized, respected, and valued for the support they provide is a measure of the compassion of a society. {Health Council of Canada, 2010}

“There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers and those who will need caregivers.”

Former U.S. First Lady Rosalynn Carter

“Family caregivers” (referred to as “caregivers” in this report) provide care and assistance for spouses, children, parents and other extended family members and friends who need support because of age, disabling medical conditions, chronic injury, long term illness or disability — regardless of care setting. In 1997, about 2.85 million Canadians were providing care for a

family member with long-term health problems. {Cranswick, 2003} Today, an estimated 5 million family members and friends are providing care —including those caring for someone at end-of-life. {Canadian Caregiver Coalition, 2012} Given our aging population, the number of caregivers and the burden on those caregivers is expected to increase.

According to the 10th annual health care survey, 26% of Canadians provided care for a family member or close friend with a serious health problem in the 12 months before the survey. {Pollara, 2007} Caregivers provide more than 80% of care needed by individuals with ‘long-term conditions’ — at home, in long-term care facilities and in hospital — and they contribute more than \$5 billion of unpaid labour annually to the health care system. {Fast et al, 2011} Replacing family caregivers with the paid workforce at current market rates and usual employee benefits and support would cost about \$25 billion. {Hollander, Guiping, & Chappell, 2009}

Caregivers are an integral part of care in all care settings. Care provided by families enables individuals to remain at home longer; it also supports the services provided in facilities.

Typically caregivers welcome the opportunity to provide care and support to a loved one. They consider it an obligation. Most caregivers expect to be called on to play a caregiving role, and they understand that the role may last a long time. However, caregiving has a profound effect on the individual — emotionally, mentally and physically. The effect of palliative caregiving can compound the impact on the individual. {Addington-Hall & Karlsen, 2000; Stajduhar & Davies, 2005}

WHO PROVIDES CARE?

Women most often fulfill the caregiving responsibilities; however, 10% of all men in Canada (approximately 1.5 million) are caregivers and their numbers are increasing. {Fast, 2001}

Caregivers come from all income levels — although typically they have household incomes below the national average. Only 35% of households with caregivers report income over \$45,000.

{Health Canada, 2002}

“Young carers” refers to anyone “under the age of 18 years who is the primary caregiver in the family due to parental illness, disability or addiction” and whose responsibilities extend “beyond what would be normally culturally expected”. {Charles et al, 2012}

Caregiving is usually provided by adults, however “young carers”, aged 12 to 17 years, are “an invisible feature of the family caregiving landscape”: they “fill in caregiving gaps and help meet the needs of family members recovering from illness or injury, managing a chronic, episodic or progressive health condition or mental illness, or at the end

of life”. {Charles et al, 2012} Based on a survey of high school students in Vancouver, 10% of students provide substantial care, assistance or support to another family member. {Charles et al, 2012} The needs of this segment of family caregivers are unique and require more consideration. Targeted programs such as the young carers programs at Hospice Toronto help youth build resilience and self esteem, and provide time for “kids to be kids”. {Hospice Toronto}

HOW MUCH CARE IS PROVIDED?

Caregiving responsibilities vary, and can grow as the family member’s condition and abilities deteriorate over time. If a crisis occurs, caregiving responsibilities can increase without notice or time to prepare.

The intensity and length of caregiving can be significant. According to an Ipsos Reid survey, on average, Canadians estimate they would spend 54 hours per week to care for a dying loved one at home, and two-thirds of Canadians say they could not devote the time needed for this care. {Ipsos-Reid Survey, 2004} Indeed, research in 2002 that looked at family caregiving in all settings of care found that over 700,000 caregivers (25%) provided more than ten hours of care per week, and 60% provided care for more than three years. {Health Canada, 2002}

BALANCING CAREGIVING AND WORK

More than three quarters of caregivers are employed and most work full time. {Fast et al, 2011} In 2007, employed caregivers in Canada provided an estimated 893 million hours of care annually, or the equivalent of 476,281 full time employees. {Fast et al, 2011}

For caregivers, work has both a positive impact — providing a form of respite and relieving the caregiver’s isolation — and a negative impact — adding to the stress of balancing competing demands and fatigue. {Reid, Stajduhar, & Chappell, 2010} Caregiving responsibilities can interfere

with the caregiver's work, and balancing work and caregiving responsibilities can be challenging. For example, frequent phone calls during work and the requirement to leave work to accompany the family member to medical appointments contribute to caregiver stress, but may not affect the client's well-being or self-esteem. {Reid et al, 2010} A Health Canada study found that 25% of family caregivers have had their employment situation affected by their caregiving responsibilities. {Fast, 2008}

Employers know that their employees will have caregiving responsibilities and that they will incur costs as a result of absenteeism and lost productivity. In 2007, over 520,000 employed caregivers missed at least one day of work per month to provide care — collectively missing nearly 1.5 million work days per month due to caregiving responsibilities. {Fast et al, 2011} In addition, over 313,000 employed caregivers reduced their hours of paid work to provide care — a collective impact of 2.2 million hours per week. {Fast et al, 2011} With the anticipated increase in demand for caregiving, the implications for economic productivity of the country are significant.

Information about the impact on work of family caregiving at the end of life is limited. In 2009, Duxbury et al found that only 3% of employed caregivers described the health status of the person they were caring for as palliative. Employees may be reluctant to share the burden at the workplace and to acknowledge that the person receiving care is dying. The Compassionate Care Benefit (CCB) allows caregivers to take a temporary leave from regular employment with income assistance to care for a terminally ill person at risk of dying within 26 weeks. {Williams, Crooks, Giesbrecht et al, 2010} Analysis of the use of this program will increase the awareness of the needs of caregivers in the palliative context.

FAMILY CAREGIVERS' EXPERIENCE IN DIFFERENT CARE SETTINGS

People nearing end of life and their families experience an immense burden of suffering. Access to high quality hospice palliative care services can ameliorate a considerable portion of this suffering. {Wright et al, 2010} In a 1992 study, the Regional Palliative Care Unit in Ottawa found that 80% of caregivers believed inpatient care on the palliative care unit “offered the best quality of life and death, even for patients who had resisted admission to a palliative care setting”. {Keizer, Kozak, & Scott, 1992} Today, hospice palliative care is recognized as a comprehensive system of services that should not be limited to hospices and specialized palliative care units. It should be provided in any setting where people die including acute care, long term care facilities, and at home. The health system is more effective and provides better care for clients nearing end of life when well-resourced hospice palliative services are in place. However, the hospice palliative services provided in different setting often vary significantly and each setting presents its own challenges for caregivers.

AT HOME

A fundamental principle of home care is that family and/or friends will provide care to enhance the publicly funded service.

Between 40 and 80 percent of people would prefer to die at home surrounded by their loved ones. {Dunlop, Davies, & Hocklye, 1989} Publicly funded home care services can help achieve that outcome — as long as family

caregivers are available to provide much of the care. Home care is designed to complement and supplement, but not replace, the efforts of individuals to care for themselves with the assistance of family, friends and community.

In many ways, home care shifts the primary responsibility for caregiving from paid staff in a facility (hospital, long-term care home) to family members. The requirement to provide care to a family member at home at end-of-life can have a profound effect on the family. The ability of family members to care for someone at home depends on: their availability, their financial ability to support the home care program, their ability to manage the physical symptoms in the home setting, and the functional ability and needs of the dying person. {Stajduhar & Davies, 2005}

Providing hospice palliative services at home is often not a conscious decision made by a family but a situation that evolves as a result of a request by the patient, a lack of knowledge about the implications, an unrealistic sense of the expectations, a sense that there was no choice, and pressure from the health system. A review of the literature by Funk et al synthesizes the home-based caregiving experience at end of life. {Funk et al, 2010} While the authors suggest caution in interpreting some results due to sample size, their findings mirror anecdotal experiences reported by many caregivers. Family caregiving at home can be:

- **Highly emotional and stressful** — Feelings are intense and conflicting. Anxiety is high and caregivers often feel helpless and hopeless as they deal with their grief and witness the deterioration of the patient. These feelings extend into the bereavement period.

- **Physically demanding** — The requirement to provide 24-hour care interferes with sleep, and the need to provide complete physical care can be taxing. {Brazil et al, 2006}
- **Challenging** — Caregivers are thrust into a role for which they have limited knowledge, ability or preparation — especially regarding symptom, pain and medication management.
- **Isolating** — Some caregivers are reluctant to leave home {Broback & Bertero, 2003} because of exhaustion, lack of spare time, and/or feelings of awkwardness talking about their circumstance. {Aoun, Kristjanson, Hudson et al, 2005}
- **Financially difficult** — When caregivers have to take time off work and/or finance special equipment and medications, it can create financial issues. About 40% of caregivers experience long-term financial pressures related to their caregiving responsibilities {Keating, Fast, & Yacyshyn, 2008}; 22% report missing one or more months of work; and 41% used personal savings to fulfill their caregiving responsibilities. {Pollara, 2007}

Despite the pressures that caregivers experience, they often negate their own needs. {Payne, Smith, & Dean, 1999} They often do not recognize themselves that they need help, nor are they typically perceived as needing support by the health care system. {Northouse, Peters-Golden, 1993; Northouse, Mood, Templin et al, 2000}

On the other hand, when caregivers are adequately supported by the health care system, they can manage well and reduce the need for more costly health care services. For example, when caregivers receive structured support, it is possible to delay the move of someone with dementia to a care facility by as much as 18 months. {Mittelman, Haley, Clay et al, 2006} Caregiver assessment tools have been developed and can be used by the health care team to understand caregivers' needs, support the caregivers' wellbeing, and provide caregivers with the ability to care for someone with a chronic life-limited illness at home.

IN ACUTE CARE

A significant proportion of people with life-limiting conditions end up in acute care hospitals. This is particularly true of people who experience organ failure or frailty who have not been engaged in advance care planning. Because their illness trajectory does not have a clear terminal phase, they can deteriorate quite suddenly and be hospitalized. When active treatment ceases to work,

The organ system failure trajectory typically has a two to five year period of decline with intermittent life threatening exacerbations and then "sudden death". The individual needs acute care for exacerbations followed by increasing care at home. {Murray, Kendall, Boyd et al, 2005; Murray, 2010}

the patient and family are advised to prepare for death. For families, the shift from talking about cure to talking about dying can be quite abrupt.

According to a study of Inpatient Palliative Care Activity (2009) in Ontario, the current acute care system continues to actively treat people who are nearing end of life when an

integrated palliative approach to care may be more appropriate and desired. In one recent study,

patients with cancer who died in a hospital or intensive care unit and their family caregivers experienced significantly more physical and emotional distress and worse quality of life at the end of life compared with patients who died at home with hospice services and in hospices. {Wright et al, 2010}

Caregivers of someone who is dying in an acute care hospital experience many of the same stresses as caregivers providing care at home. Caregiving in an acute care setting can be:

- **Highly emotional and stressful** — Caregivers often feel helpless and hopeless as they watch the patient deteriorate. They may not have the same opportunities to talk or say the things they want to say in an acute care setting.
- **Tiring** — Caregivers experience fatigue when they have to commute back and forth from the hospital. They often end up missing meals. They often have to assist with the person's physical care — bathing, feeding and moving. As the patient's health deteriorates, they may end up sleeping in the hospital in a chair or on a cot.
- **Isolating** — Some caregivers are reluctant to leave the person alone in the hospital or to take a break from their caregiving routine at the hospital. They can become isolated from friends and other supports.
- **Financially difficult** — Caregivers may not experience as many extraordinary expenses as they do caring for someone at home but they do bear the costs of having to travel to and from the hospital, including parking and meals. In some cases, families pay to have extra nursing support for a family member in hospital or to provide a private room.

Providing the integrated palliative approach to care in acute care settings can help resolve emergency room congestion and issues related to patients in alternate levels of care (ALC). More importantly, it can relieve families of unnecessary suffering and grief during an already stressful time in their lives. {Quality Hospice Palliative Care Coalition of Ontario, 2010}

IN LONG-TERM CARE

Residents in long-term care (LTC) facilities have a limited life expectancy and most would prefer to remain in the facility at end-of-life. However, long-term care facilities are not typically well resourced with palliative care expertise, and their staff are increasingly challenged by the complex decisions associated with caring for dying residents. Studies confirm the need to provide education for staff to enhance their ability to provide hospice palliative care services and to ensure they have easy access to support from hospice palliative care specialists.

Family caregivers are often intensely involved in the care of residents in long-term care homes, visiting regularly and helping with care and activities of daily living. For caregivers, long-term care facilities present challenges similar to those experienced in acute care settings. Family caregiving in a long-term care facility can be:

- **Highly emotional and stressful** — As in other settings, caregivers often feel helpless and

hopeless as they watch the patient deteriorate. A significant proportion of residents of long-term care facilities have dementia, which makes providing care more stressful

- **Tiring** — Caregivers experience fatigue traveling to and from the long-term care home.
- **Isolating** — Some caregivers are reluctant to leave the person alone in the long-term care home or to take a break from their caregiving routine. They can become isolated from friends and other supports.
- **Financially difficult** — For some families, paying the extra costs associated with having a family member in a long-term care home — often for months or years — can be financially challenging.

SUPPORTING CAREGIVERS

The paradox for family caregivers is that they want to preserve hope and yet often regret not knowing that death was imminent and missing opportunities for meaningful end-of-life communication. {Doka, 2010}

WHAT HELPS CAREGIVERS COPE?

Notwithstanding the challenges and stresses of caregiving discussed above, caregivers report that the experience was positive and that they felt appreciated for their caregiving. {Stajduhar, Martin, Barwich et al, 2008} A caregiver's ability to cope with the stresses is most influenced by the:

- Caregiver's approach to life
- Patient's experience with their illness
- Patient's recognition of the caregiver's contribution to his or her care
- Quality of the relationships between the caregiver and the dying person
- Caregiver's sense of security, including support from family, friends and the healthcare system.

Caregivers need ongoing support to help them provide care for family members with chronic life-limiting illnesses — to realize the person's full potential to live even when he or she is dying. This support should begin early in the disease trajectory. Few Canadians (44%) discuss end-of-life care with a family member despite the fact that most (83%) agree that it is very or extremely important to do so. {Ipsos-Reid Survey, 2004} Although half of Canadians feel it is very or extremely important to discuss end-of-life care with a doctor, only 9% have had that conversation. {Ipsos-Reid Survey, 2004} Caregivers may need support to be able to have those conversations and learn what the family member's wishes are.

Despite the fact that caring for a loved one at home posed a great financial and emotional burden, those whose loved ones died at home and had access to home care reported greater overall satisfaction with the caring experience. Given appropriate professional support systems, home-based care at the end of life is preferable for most caregivers. {Singer, Bachner, Shvartzman et al, 2005} However, as the family member's disease progresses, caregivers may develop misgivings about providing palliative care at home — due to caregiver exhaustion, concern about access to medical care, risk of physical injury due to the limitations of the home environment, and increasing complexity of care required to manage pain and other symptoms. {Stajduhar & Davies, 2005} The right supports at this stage can be key to people being able to die at home.

Support is particularly important for caregivers providing care for someone with dementia, which is extremely demanding. These caregivers spend at least 46 hours per week assisting the person with activities of daily living and instrumental activities of daily living. {Schulz et al, 2003} They experience high levels of depression — often because they believe that the family member is in pain but unable to communicate. {Schulz et al, 2003}

The Canadian Caregiver Coalition (CCC) Caregiver Strategy describes the five key elements that address the priority needs identified by family caregivers. They are:

- Safeguarding the health and wellbeing of family caregivers and increasing the flexibility and availability of respite care
- Minimizing excessive financial burden placed on family caregivers
- Enabling access to user friendly information and education
- Creating flexible workplace environments that respect caregiving obligations
- Investing in research on family caregiving as a foundation for evidence-informed decision-making areas of support. {Canadian Caregiver Coalition, 2008}

If all elements of the strategy are implemented then the health and social services will be able to provide adequate support tailored to the diverse needs of caregivers. Family caregivers would be assessed for their specific needs at regular intervals — a process that acknowledges changing capacity over time. They would also have easy access to training and information about all aspects of caregiving, including health care outcomes, impacts of policies and services, best practices, economic dimensions and psychosocial impacts. Families would be informed about the financial and legal implications of caregiving to help them make informed decisions about where and how the person’s care would be provided. Those who had to leave paid employment or curtail self-employed work in order to provide care would be able to access job protection provisions and income support. Financial measures would offset caregiving expenses and provide employment related benefits for caregivers. {Canadian Caregiver Coalition, 2008}

WHAT CAN THE HEALTH SYSTEM DO?

The place of care is, and should be, less important than the care people receive. {Murray, Fiset, Young et al, 2009}

All health care settings should be included in the efforts to ensure that all individuals and their caregivers receive the benefits of the integrated palliative approach to care — which includes recognition of and support for caregivers. A person’s preferred setting of care should be defined in collaboration with the patient and his or her family, allowing for individual choice in determining how to address unique needs and desires for support. Each setting should ensure adequate resources to provide high quality, safe care. In settings that rely heavily on caregivers, such as home care, services should be increased to support the family and provide respite.

Professional care teams in all settings should commit to working in partnership in order to assure the patient and family receive integrated and seamless access to the care and support they need. Care pathways should be defined, and caregiver assessments conducted early in the disease trajectory and frequently thereafter. The team should be knowledgeable about community services, such as community programs and support groups, and about web-based resources, such as the Canadian Virtual Hospice (www.virtualhospice.ca), and should refer caregivers appropriately.

Through effective advance care planning, the health team, client and family can make more informed decisions about when to stop active treatment. The ultimate goal is to enable more individuals to have timely access to the integrated palliative approach to care and support throughout the illness trajectory and across all settings.

Integrating hospice palliative care across the health care system is critical to ensure that:

- Pain and symptom control, psychosocial distress, spiritual issues and practical needs are addressed with patient and family in all settings;
- Family caregivers are acknowledged for their contribution and receive consistent information, education and training;
- Care is patient-centred and respects the individual's values and goals and role in decision-making regarding the plan of care;
- Communication between providers at transition points in care, or settings of care, minimizes variation and inconsistency. {Collins, Jones, Peres et al, 2008}

This integrated approach to care will enhance caregiver confidence and improve care for palliative patients.

WHAT SHOULD EMPLOYERS DO?

Employers know their employees will be involved in family caregiving. While their caregiving responsibilities may detract from work, their ability to continue to work can be important and beneficial for both the employee and the employer.

Employers can support employees who are caregivers by offering:

- **Flexibility** — Working caregivers repeatedly emphasize the importance of flexible work hours and being able to take unscheduled time off and/or a leave of absence to handle caregiving responsibilities. Flexible work arrangements can include the adjusting of regular work hours, job sharing, telecommuting and the provision of family leaves. The ability to work from home is another form of flexibility.
- **Information and Assistance** — Employers are a trusted source of information and can help caregivers by providing information on community resources, services offered through the company, wellness programs and access to resources about caregiving. It is increasingly important and valuable for employers to be knowledgeable of programs and services that are available.

GlaxoSmithKline (GSK) provides employees a leave from work so they can provide care and support to an immediate family member in cases of critical or terminal illness or other extraordinary circumstances. The benefit provides for up to 13 weeks leave over a two-year period. Those with at least three years of service can receive the 13-week leave at full salary.

Paul N. Lucas, President & CEO, GSK, 2011

- **Emotional Support** — Employers who demonstrate genuine caring and encourage their workers to spend as much as time as possible with their dying loved one provide important support for working caregivers and can engender support from co-workers and supervisors at the workplace. Research has shown that lower levels of supervisor support for caregiving are associated with higher levels of work-family conflict.
- **Other Support** — Caregivers who work outside the home often need help with legal, financial, and health insurance matters. Help processing the various forms can provide relief from some of the often enormous administrative burdens. Wellness programs can help caregivers address their own health care needs. A “donated sick leave policy” allows employees’ accrued sick leave to be donated to a leave pool for sharing with caregiver employees in certain circumstances.

WHAT SHOULD GOVERNMENTS DO?

Governments should strive to establish the right balance of responsible fiscal and social policy development to enable support and empowerment. Government can support caregivers through:

- **Tax Measures** — Enhancing the financial tax credits¹ for caregivers would help compensate for expenses incurred by families who must purchase services, equipment and supplies that assist families to live independently at home. A refundable tax credit, the Primary Caregiver Tax Credit, has been established in Manitoba (Manitoba Finance). Quebec offers a tax credit to caregivers supporting someone who is unable to live alone, and includes those who cohabit the dwelling of an eligible relative and the spouse of a person aged 70 or more. {Revenu Quebec, 2012} Establishing a registered savings plan specifically for caregiving would also complement caregiving tax vehicles.
- **Financial Support Programs** — The provision of caregiver allowances does not fully compensate people for their efforts, but it does acknowledge the value of caregiving. This approach is used by several countries, including Australia, Norway, Sweden and the United Kingdom, and also by the province of Nova Scotia, where caregivers are entitled to a caregiver allowance of about \$400 per month through the Caregiver Benefit Program. {Nova Scotia, 2011} Caregiver allowances, like allowances provided to low income families for children, enhance the ability of caregivers to access services and thereby improve their ability to cope and keep their family member at home. In one study, use of counseling and support programs could delay placement by up to 1.5 years. {Mittelman et al, 2006} Developing financial support programs — special funds that can be accessed by those who are not covered by other income or pension plans — can also help by, for example, supporting older caregivers who have small pensions and limited means to cover the expenses of caregiving. Establishing an innovation fund could provide the funding required to test different interventions to support caregivers and identify best practices that could be shared between jurisdictions.

¹ A *tax credit* is an amount that is subtracted from the individual’s tax payable. A *non-refundable tax credit* only applies to those who have taxable income. *Refundable tax credits* apply to those who meet the criteria for the benefit even if they do not have a taxable income

- **Labour Code** — Modifications to the labour code — separate and distinct from Employment Insurance — could provide valuable support for family caregivers. For example, the Compassionate Care Benefit (EICCB) could be modified to include those who are self-employed and would address the long-term and often episodic nature of caregiving for older individuals. Strategies could include: incentives and compensation (such as maintaining employment benefits such as pension, sick leave and vacation entitlement) for caregivers who are shut out of the workforce because of caregiver responsibilities; and support for the reintegration of caregivers into the labour market after a prolonged caregiving episode. Ontario's new Family Caregiver Leave {Jeffrey, 2012} is a promising plan that builds on the existing family medical leave allowing an additional eight-week protected leave from work.
- **National Strategies** — A Caregiver Strategy demonstrates the government's recognition of caregivers as a group with unique issues and needs. In 2011 Manitoba proclaimed a provincial Caregiver Recognition Act, the first in Canada. {Rondeau, 2011} A national Palliative and End-of-Life Care Strategy that aligns with other national strategies could increase the awareness of and commitment to comprehensive integrated palliative care — including support for caregivers.
- **Employer Incentives** — Employer incentives could reward those with caregiver-friendly policies. As our population ages, the issue of work-family balance will become a serious problem in Canada. Economic incentives can stimulate creative employment practices in order to ensure that talent and intellectual capital is retained while supporting family members to fulfill their caregiving responsibilities. As the fifth largest employer in the country, the federal government should ensure its policies and practices support employees with caregiving responsibilities.

WHAT SHOULD COMMUNITIES DO?

Communities can play a key role in raising awareness. They should encourage public discussion about death and dying, and the importance of the integrated palliative approach to care. The type and quality of care that people receive at end of life depends in large part on our ability and willingness to talk about and plan for death while still enjoying life.

Communities should also find ways to support caregivers by demonstrating sensitivity to this special and important time in a person's life, and showing compassion for the caregivers' health and well-being.

CONCLUSION

While today's seniors will be the healthiest in Canada's history, they will still develop chronic diseases as they age and ultimately die with and from these conditions. We can be better prepared and more sensitive in our approach to the care they receive in their last years and months of life by:

- Encouraging all Canadians to discuss and plan for end-of-life
- Being prepared to support and provide care for a family member with a chronic, life-limiting condition
- Discussing and preparing family members for future caregiving responsibilities
- Formally assessing the needs of caregivers and providing them with care, support and resources to enable their wellbeing
- Showing compassion and consideration for caregivers
- Providing a health system that delivers quality integrated palliative care throughout the disease trajectory.

There needs to be more discussion about death and dying, and the importance of high quality hospice palliative care. Family caregivers are essential at end of life. Canadians need to actively and openly commit to caregiving, and the health care system, employers, governments and communities must commit to supporting them.



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