

Federal
Election
Kit

2015

Quality End-of-Life Care Coalition of
Canada

FORWARD

2015 QELCCC ELECTION KIT

The QELCCC Advocacy Committee is pleased to provide the members with a tool kit that outlines our position statements as they are defined in the Blueprint for Action. For each position statement, we have included a brief context, specific “asks” and questions that can be posed to MPs.

It is important to note that the “asks” do not include any direct reference to individual QELCCC members, rather they focus on advancing an integrated palliative approach to care and only specify QELCCC led projects (e.g. The Way Forward).

WHAT THE KIT IS:

- A tool to support consistent messaging to the Federal Government
- Reference for QELCCC members
- Data resource to support messages
- Source for advancing the Blueprint for Action

WHAT THE KIT IS NOT:

- A prescriptive document
- A complete set of advocacy asks
- A comprehensive advocacy strategy – each members will have their own

We hope that you will find the kit useful in supporting your advocacy work. As the Coalition Advocacy we will be referring to the messaging in the kit for our communications over the next year.

The QELCCC Advocacy Committee

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ABOUT THE QUALITY END OF LIFE CARE COALITION OF CANADA

The members of the Quality End of Life Care Coalition of Canada believe that all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice. The members believe that to achieve quality end-of-life care for all Canadians there must be a well-funded, sustainable national strategy for an integrated palliative approach to care. It is the mission of the Coalition to work together in partnership to achieve this goal.

Member Organizations

- ALS Society of Canada
- Canadian AIDS Society
- Canadian Association for the Deaf – Association des Sourds du Canada
- Canadian Association of Occupational Therapists
- Canadian Association for Spiritual Care
- Canadian Association of Social Workers
- Canadian Breast Cancer Network
- Canadian Cancer Action Network
- Canadian Cancer Society
- College of Family Physicians of Canada
- HealthCareCAN
- Canadian Home Care Association
- Canadian Hospice Palliative Care Association
- Canadian Lung Association
- Canadian Medical Association
- Canadian Nurses Association
- Canadian Pharmacists Association
- Alzheimer Society of Canada
- Canadian Partnership Against Cancer
- Canadian Society of Palliative Care Physicians
- Canadian Society of Respiratory Therapists
- Canadian Working Group on HIV and Rehabilitation
- Catholic Health Alliance of Canada
- Heart and Stroke Foundation of Canada
- Huntington Society of Canada
- The Kidney Foundation of Canada
- Mental Health Commission of Canada
- National Initiative for the Care of the Elderly (NICE)
- Ovarian Cancer Canada
- Pallium Foundation of Canada
- Saint Elizabeth Health Care
- Women’s Inter-Church Council of Canada
- Technology Evaluation in the Elderly Network
- Inuit Tapiriit Kanatami

Associate Members

- Canadian Caregiver Coalition
- Canadian Arthritis Patients Alliance
- Canadian Virtual Hospice
- Canadian Network of Palliative Care for Children

AN URGENCY FOR AN INTEGRATED PALLIATIVE APPROACH TO CARE

According to Statistics Canada, projections show Canada will have an exponentially increasing elderly population in the near future. In 2009, there were roughly 1.3 million people age 80 or over. It is projected to increase to 3.3 million by 2036.ⁱ Is it therefore disconcerting that only 16% to 30% of Canadians currently have access to or receive tertiary or specialist hospice palliative and end-of-life care service.ⁱⁱ This is despite the fact that Canadians agree that this approach to care greatly reduces the stress and burden placed on the family.ⁱⁱⁱ There is strong and growing evidence that early provision of a palliative approach to care, combined with treatment, leads to better outcomes for persons and their family caregivers, including: improvement in symptoms, quality of life and patient satisfaction; less burden on caregivers; more appropriate referral to and use of hospice; and less use of intensive care than treatment alone.^{iv}

An integrated palliative approach to care focuses on meeting a person's and family's full range of needs – physical, psychosocial and spiritual – at all stages of a life-limiting illness, not just at the end of life. It reinforces the person's autonomy and right to be actively involved in his or her own care – and strives to give individuals and families a greater sense of control. It sees hospice palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging. It provides key aspects of palliative care at appropriate times during the person's illness, focusing particularly on open and sensitive communication about the person's prognosis and illness, advance care planning, psychosocial and spiritual support and pain/symptom management. As the person's illness progresses, it includes regular opportunities to review the person's goals and plan of care and referrals, if required, to more specialized palliative care services.

In a recent public opinion poll, the vast majority of Canadians (97%) supported an integrated palliative approach to care that focuses on meeting a person's and family's full range of needs – physical, psychosocial and spiritual – at all stages of a life-limiting illness, not just at the end of life.^v

An integrated palliative approach to care can improve the health and quality of life for individuals with serious illnesses that are likely to cause death. This approach provides patients with a greater sense of control over their lives and care. It also results in more effective use of health care resources, including palliative care specialists who are currently in limited supply across Canada.

The federal government plays a critical role in making an integrated palliative approach to care a reality across Canada. Below are four key issues that must be addressed through federal leadership:

KEY ISSUE 1: ENSURE ALL CANADIANS HAVE ACCESS TO AN INTEGRATED PALLIATIVE APPROACH TO CARE

KEY MESSAGE

Only 10% of people die suddenly.^{vi} 90% of Canadians will need care and support at the end of life, with the majority (85%) requiring access to an integrated palliative approach to care across all setting of care - primary care provider, in the home, in long-term care homes, in hospital or in other community settings.

When someone is diagnosed with a life-limiting illness, an **integrated palliative approach to care** focuses on meeting a person's and family's full range of needs – physical, psychosocial and spiritual – at all stages of a life-limiting illness, not just at the end of life.

As the number of individuals with complex conditions increases, we must ensure that all Canadians have access to palliative services integrated with their other care that will help them manage symptoms, enhance their lives, give them a greater sense of control and enable them to make informed decisions about the care they want.

WHAT WE'RE ASKING FOR

1. Adopt The Way Forward vision, mission and principles into a national action plan and allocate targeted funds to facilitate implementation of the integrated palliative approach to care across the country.
2. Embed an integrated palliative approach to care into all national health strategies -cancer, heart health, diabetes, lung, HIV/AIDS, chronic disease management, mental health, Aboriginal health and seniors' strategies.
3. Continue funding The Way Forward (TWF) as a catalyst to support an integrated palliative approach to care across all settings (acute care, long term care, and home care). Phase 2 would focus on building capacity and implementation.

QUESTIONS FOR CANDIDATES

1. Does your party support an integrated palliative approach to care in all settings of health care?

2. How would your party work to ensure all Canadians receive quality end-of-life-care in the setting of their choice?
3. How would your party ensure that the federal government provides an integrated palliative approach to care for the populations it has direct health responsibility for (First Nations, veterans, prisoners and refugees)?
4. How would your party ensure that all Canadians understand and receive an integrated palliative approach to care across the country?

KEY ISSUE 2: RECOGNIZE, VALUE AND SUPPORT THE VITAL ROLE OF FAMILY CAREGIVERS

KEY MESSAGE

Family caregivers are individuals (family members, neighbours, friends and other significant people) who take on a caring role to support someone with diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness.

In 2012, 13% of Canadians (3.7 million) aged 15 and older reported providing end-of-life or palliative care to a family member or friend at some point in their lives.^{vii} Caregiving, although a rewarding experience often comes with many challenges:

- Family caregivers identified a lack of necessary resources or abilities to provide end-of-life care in their own home. Specifically, home care services, financial assistance, paid time off from work and home modifications were among the supports listed by the one in six family caregivers who would have preferred providing palliative care to their loved one in their own home.
- Family caregivers often face difficulties getting information from health care professionals, finding local support services and navigating the health care system^{viii}. Three quarters of Canadians would seek more information on hospice palliative care services from their family physician^x however; family physicians and nurses reported needing greater knowledge to feel comfortable discussing a palliative approach to care with patients^x and need guidance on when to have this conversation and on what options are available locally^{xi}.

WHAT WE'RE ASKING FOR

1. Expand the National Advance Care Planning initiatives to include family caregivers in conversations with health professionals and care recipients.
2. Minimize undue financial burden faced by family caregivers by:
 - Enhancing the Compassionate Care Benefit to provide a flexible 52 week benefit that could be accessed in increments of 1 week throughout the care recipients' journey - from initial diagnosis of a life-limiting illness to the last weeks of life.
 - Modifying the Family Caregiver Tax Credit to be refundable and expand the definition of care recipient to be broader than that of the family caregivers' dependent.
3. Expand the 'Employers for Caregivers' initiative to be a resource for employers across Canada that would:
 - Provide practical advice and support for employers seeking to develop family caregiver friendly policy and practice and retain skilled workers.
 - Identify and promote the business benefits of supporting family caregivers in the workplace.
 - Influence government and employment policy and practice to create a culture which supports family caregivers in and into work
 - Safeguard the health and well-being of family caregivers by supporting enhanced education for health care professionals in communicating with family caregivers, recognizing their unique needs and providing information resources.

QUESTIONS FOR CANDIDATES

1. Has your party included family caregivers in your platform / policies?
2. How would your party leader issue a proclamation recognizing the role and value of family caregivers?
3. What financial measures would your party introduce to support family caregivers looking after a loved one with a life-limiting illness?
4. What incentives would your party provide employers to support caregiver friendly workplaces?

KEY ISSUE 3: IMPROVE QUALITY AND CONSISTENCY OF PALLIATIVE CARE

KEY MESSAGE

The delivery of consistent, high-quality palliative care is dependent on three fundamental factors:

- 1) An appropriately trained, adequately sized health care workforce training in the palliative approach to care and palliative care workforce
- 2) Integrated performance accountability framework that include providers, , educators and the health system.
- 3) Ongoing research and knowledge translation in integrated palliative approach to care

Although basic palliative care competencies have been established for the fields of medicine, nursing and social work, they have not been consistently integrated into the curricula of academic institutions across the country. National competencies should be developed for other health care workers; and steps taken to ensure consistent integration of the competencies into the curricula of all training institutions. Competencies should address all levels of expertise, ranging from basic competencies for all health care providers to expert skills for palliative care specialists.

An integrated palliative approach to care focuses on meeting a person's and family's full range of needs – physical, psychosocial and spiritual – at all stages of a life-limiting illness, not just at end of life.

Currently there are not enough palliative care experts to meet the demands of service delivery, education, and research. The pressure will continue to increase as Canada's population increases, highlighting the need for integrated workforce planning that addresses quality-end-of-life care across Canada.

What we're asking for

1. Establishment of national standards for palliative care education for all health care providers at all stages of their professional education, and in appropriate to the care setting(s) in which they practice.
2. Policy that ensure: :
 - a. All health care providers are trained in the basic principles and practices of palliative care
 - b. Enhanced training is provided for those who frequently care for people with advanced conditions
 - c. Expert training is provided for palliative care specialists and educators
3. Funding for the development of an integrated workforce plan that will project resource and training requirements for implementing The Way Forward.

4. Continue funding palliative care research and the integration of findings into policy and practice.
5. Establish national performance indicators and reporting systems for an integrated palliative approach to care. .

QUESTIONS FOR CANDIDATES

1. How will your party support development and implementation of national palliative care competencies for health care providers?
2. Will your party support establishment of federal funding to develop an integrated workforce plan for Canada?
3. Does your party support an increase in federal funding for integrated palliative approach to care research initiatives?
4. How will your party support development of national performance indicators and reporting systems for an integrated palliative approach to care?

KEY ISSUE 4:

ENCOURAGE CANADIANS TO ENGAGE IN ADVANCE CARE PLANNING (ACP)

KEY MESSAGE

Advance care planning is a fundamental priority in establishing an integrated palliative approach to care

An integrated palliative approach to care will not be a priority in our health care system until it is understood and a priority for Canadians. A truly integrated palliative approach to care should start earlier – before people become frail or ill – with a strong focus on advance care planning.

Advance care planning – the conversations about what people value and the kind of care they want – begins when they are well, and continues throughout their lives. It is grounded in a person-centred, holistic approach and empowers individuals to make choices. By talking openly and often about their health and their treatment options, Canadians are more involved in their care and better able to make decisions.

WHAT WE'RE ASKING FOR

1. Invest in ACP initiatives to leverage its success to educate Canadians and raise awareness about the importance of advance care planning.
2. Integrate ACP initiative elements in to the National Strategy on Financial Literacy and other senior targeted initiatives.
3. Provide resources to engage physicians, nurses and other health care providers and family caregivers in a dialogue with all patients about the importance of advance care planning.

QUESTIONS FOR CANDIDATES

1. Does your party recognize the value of ACP initiatives and would your party continue to support this important initiative?
2. How will your party encourage Canadians to talk about death and dying as part of life?

ⁱ Population Projections for Canada, Provinces and Territories – 2009-2036, Statistics Canada, Catalogue 91-520-XIE.
<http://www.statcan.gc.ca/daily-quotidien/100526/dq100526b-eng.htm>

ⁱⁱ Canadian Institute for Health Information, *Health Care Use at the End of Life in Western Canada*. Ottawa: CIHI.

ⁱⁱⁱ Smith TJ, Temin S, Erin R, et al. American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care. feb 26, 2012. Accessed from www.asco.org. march 2012.

^{iv} Smith TJ, Temin S, Erin R, et al. American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care. feb 26, 2012. Accessed from www.asco.org. march 2012.

^v A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). 46

^{vi} William M. Plonk, Robert M. Arnold. *Journal of Palliative Medicine*. 2005, 8(5): 1042-1054.
doi:10.1089/jpm.2005.8.1042

^{vii} Statistics Canada, Study: End-of-life care, 2012. October 2014.

^{viii} The Way Forward. (2014) The Caregiver Voice: Consultations with Family Caregivers. Accessed from
<http://www.hpcintegration.ca/resources/family-caregivers.aspx>

^{ix} Harris Decima 2013, What Canadians Say: The Way Forward Survey Report December 2013 (page 44). Accessed from
<http://www.hpcintegration.ca/resources/what-canadians-say.aspx>

^x Ipsos Reid. (2014)The Way Forward Survey: General/Family Practitioners and Nurses in Primary Care (page 7). Accesses from <http://www.hpcintegration.ca/resources/health-care-professional-research/primary-care-research.aspx>

^{xi} Ipsos Reid. (2014)The Way Forward Survey: General/Family Practitioners and Nurses in Primary Care (page 8). Accesses from <http://www.hpcintegration.ca/resources/health-care-professional-research/primary-care-research.aspx>