New Challenges and New Horizons:
How do we move forward with hospice palliative care?

Sharon Baxter, Executive Director
May 5\textsuperscript{th}, 2016
Vancouver, BC
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Building on our past how do we make our new challenges possible opportunities. How do we define ourselves as we move forward?
An action plan for the future.

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Association canadienne de soins palliatifs
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2. The Quality of Death Index 2015
3. Current challenges including language, PAD and universal coverage
4. Opportunities to move forward – The Way Forward Initiative and ACP
5. Key Messages and a Call to Action
Question 1

In 2014 we completed a Harris Decima poll of over 3,000 Canadians across Canada. We read a description of Hospice Palliative Care services and asked “are you aware of these types of services?”

What percentage of Canadians do you think responded yes?
Awareness of Hospice Palliative Care Services

**Question 18**
One type of health care brings together a variety of services to relieve the suffering and improve the quality of life for persons living with or dying from a chronic illness, as well as making services available for family members of these individuals. Are you aware of these types of services?

- **Yes**: 49%
- **No**: 51%

Base: All respondents (n=2,976)
Type of Patient of Hospice Palliative Care

Question 24
To your knowledge, are hospice palliative care services available for...?

- To all people at the end of their life regardless of their illness
- Only patients dying of a life threatening disease like cancer or HIV/AIDS
- Don't know

Base: All respondents (n=2,976)

*Comparable tracking data is not available
Knowledge of Locations Hospice Palliative Care is Offered

Question 22
To the best of your knowledge, is hospice palliative care offered in the following locations?
% Yes

- In a long term facility or nursing home: 74%
- In a hospital: 63%
- In some other facility in your community: 57%
- In your own home/patients home: 49%

*Comparable tracking data is not available*
Support for Hospice Palliative Care

Question 30

Hospice palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through pain and symptom management, including physical, psychosocial and spiritual. Care in the last days and weeks of life is just one component of palliative care. Overall, what is your attitude towards this type of approach to end-of-life care?

![Chart showing support for hospice palliative care. 66% are very supportive, 30% are somewhat supportive, 2% are somewhat opposed, and 2% are very opposed. Base: All respondents (n=2,976).]
End-of-Life Care Setting Preference Vs. Expectation

Question 13
When thinking about end-of-life, is your preference to die in your home, in a hospital, or another health care facility?

Question 14
And thinking about the care you will likely need in the months before the end-of-life, during those months, do you expect to receive the bulk of your care in your home, in a hospital, or another health care facility?

Q13 Base: Valid responses (n=1,691)
Q14 Base: Valid responses (n=1,772)

End-of-life Death Setting Preference
- Home: 75%
- Hospital: 14%
- Other health care facility: 12%

End-of-life Care Setting Expectation
- Home: 52%
- Hospital: 26%
- Other health care facility: 22%
Views on Planning for End-of-Life Care

Question 26

Which of the following statements comes closer to the way you feel?

- People should start planning for end-of-life care when they are healthy
- People should start planning for end-of-life care when they are diagnosed with a chronic illness
- People should start planning for end-of-life care when they are diagnosed with a life-threatening illness
- You can't plan for end-of-life care, it just happens when you need it

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<th>Total</th>
<th>People should start planning for end-of-life care when they are healthy</th>
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<td>16%</td>
<td>19%</td>
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Base: All respondents (n=2,976)

*Comparable tracking data is not available
Have you ever talked to a family member, doctor, lawyer, friend, or financial advisor about your end-of-life care preferences?

Note: This is a multiple choice response

Base: All respondents (n=2,976)
Importance of Discussion About End-of-Life Preferences

Question 16

In your opinion, how important is it to discuss one’s end-of-life care with...?

- Extremely important
- Very important
- Somewhat important
- Not very important
- Not at all important

Base: All respondents (n=2,976)
Sources of Information on Hospice Palliative Care

Question 25
If you were in need of information of hospice palliative care services, to which of the following sources would you go for information?

- Family physician
- A community health centre
- A public health or community nurse
- A provincial telephone or tele-health service
- A pharmacist
- Other

Base: All respondents
2013: n=2,976
2003: n=1,055
The 2015 Quality of Death Index
Ranking palliative care across the world

Commissioned by the Economist report and Lien foundation
80 countries were assessed
How did Canada do?

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs
The 2015 Quality of Death Index
Ranking palliative care across the world

A report by The Economist Intelligence Unit

Commissioned by

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs
Overall scores

Canada came 11th. In 2010 we came 9th.
2.1 Palliative and healthcare environment category Canada ranked 18th
This scale explains how HPC is integrated into the health care system. The goal of The Way Forward Initiative.
2.4 Capacity to deliver palliative care. Canada ranked 9th.
If every health care professional has palliative care in their basic education, then no one will come out not understanding pain management, how to communicate with patients and families or that psychological, social and spiritual care are part of palliative care, not an optional extra.

Sheila Payne, International Observatory on End of Life Care
Lancaster University, UK
Rank score 22\textsuperscript{nd}

Government funding is essential in order to increase access to care across all settings.

As more Canadians remain at home or in Long Term Care for longer at the end of their lives the cost of care has increase vs. remaining in acute care at the end. But this is what Canadians want.
Rank score 6th

There were a number of parts to this ranking including:
1. Access to opioids and ease of administrating them
2. Availability of psychological support
3. Ability and willingness of doctors to involve patients in their own care and accommodate choices and
4. Bereavement services
Community efforts are also important when it comes to raising awareness of palliative care and to encourage more people to talk about death and dying and I would add Advance care planning. This is the mandate of the Quality End-of-Life Care Coalition of Canada.
So how do you think we did?

- So we didn’t improve over 2010 (actually lost 2 ranks) and our issues around cost and integration into health care are still issues.
- But it begs the question that how did almost all of western Europe do better than Canada around costs.
In summary

We have heard what Canadians said in the Harris Decima Poll. We know our international rankings in the Death Indexes.

What are our future challenges?
And what about language

In Canada hospice palliative care programs and services are the same service but can look different by the needs of the patient, what setting of care, what the patient is dying of, how they are dying and the capacity of the family and friends to assist with care. Whereas in the US hospice and palliative care are considered different programs and are quite divided.
"to be responsive to the needs of diverse populations and jurisdiction across Canada, individual provinces and perhaps even programs will have their own understanding of the terms “palliative”, “end-of-life”; and “hospice palliative care”. A lack of a unified national definition of these terms should not diminish the strength of and commitment to the underlying philosophy of compassionate, timely, comprehensive care, education and support for all individuals living with (or eventually facing) terminal illness, life-threatening disease, trauma or aging."

(2008 and reviewed in 2015)
Please ponder….

Is end of life the last 17 days of life and hospice palliative care is the program and service that can be provided over days, months and possibly years.

or

Does end of life start when we get sick, become of an advanced age and that hospice palliative care be the services at the last few months of life.

It is a differing perspective that leads us to this confusion.
But language continues to be an issue. They want to call it supportive care -- pretty much anything besides hospice palliative care.

The truth

People don’t feel comfortable talking about dying and death. But this must change if we want to broaden the conversation -- with patients, caregivers and health care professional. But what is the right trigger for these conversations? Often the family doctor but could be another trigger.
And the challenging issue of Legislative Options for Medically Assisted Dying
Moving forward after *Carter V. Canada*
The way we die is changing. Across Canada, we are seeing a wave of change in care for people faced with frailty and/or chronic life-threatening illnesses and choices at end of life. Palliative care services – once only offered in the last days or weeks of life to people designated as dying – need to be better integrated with treatment services to enhance people’s quality of life throughout the course of their illness or the process of aging.
The facts

It would be a shame if a Canadian were to choose physician-assisted death (PAD) or now called Medical Assistance in Dying (MAID) when their pain and symptoms are poorly managed and they were never referred to hospice palliative care.

We need to make sure our government is **focused on delivering quality end-of-life care services along a full spectrum of illness trajectories options before physician-assisted death.**
CHPCA’s stance

The CHPCA believes the following key messages:

• Hospice palliative care does not include physician assisted death.
• Hospice palliative care does not hasten or prolong death.
• Hospice palliative care strives to end suffering not life.
• Canadians need universal access to hospice palliative care including good pain and symptom management.
• All patients deserve access to information about end-of-life options, including physician-assisted death.
What we hope to see

The CHPCA would like to see the following objectives achieved:

• A federally commissioned strategy for hospice palliative care that would work towards ensuring universal access to for all Canadian citizens.

• A national awareness campaign for hospice palliative care including Advance Care Planning (www.advancecareplanning.ca) which would inform Canadians of the options available to them at end of life.

• Readily available access to resources and information for physicians, caregivers and patients regarding their end-of-life care options and physician-assisted suicide.
• The protection of Canadian health care workers in the hospice Palliative care field including the option for them to opt out of providing MAID should they choose.

• Clear and informed legislation regarding MAID developed federally to be enacted by provincial governments/institutions.
Another challenge is how hospice palliative care in integrated into the health care system. We are looking at specialist hospice palliative care and the palliative approach to care in primary care.

We know more than 65% of patients have their care provided by primary care and may never be referred to HPC. And that might be fine.
Figure 5: Four Main Theoretical End-of-Life Trajectories

- **Sudden Death**: High function at the start, followed by immediate death.
- **Terminal Illness**: High function decreases gradually over time, ending in death.
- **Organ Failure**: High function gradually decreases over time, ending in death.
- **Frailty**: High function decreases gradually over time, ending in death.

The Palliative Approach to primary care

- Dying is Part of Living
- The Challenge: the way we die is changing
- The Opportunity: closing the care gap
Vision

All people in Canada who are aging and/or have chronic conditions will receive the benefits of an integrated palliative approach to care.

GOALS OF AN INTEGRATED PALLIATIVE APPROACH TO CARE

1. Canadians will talk with their care providers about advance care planning, and discuss their wishes early and often as their illness progresses or as they age.

2. People who are aging, frail and/or have chronic illnesses will receive palliative care services integrated with their other care in the setting of their choice.

3. People who are aging, frail and/or have chronic illnesses will receive consistent, seamless integrated care if/when they must change care settings.

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs
The National Framework

- Promote a Culture Shift
- Establish Common Language and Terminology that supports dying as part of living
- Educate and Support Providers
- Engage Canadians in Advance Care Planning
- Create Caring Communities
- Adapt an Integrated Palliative Approach to Provide Culturally-Safe Care, including with and for Canada’s First Peoples
- Develop Outcome Measures and Monitor the Change
Some opportunities for the future ....

• Increase media coverage and the use of social media

• More players at the table including 38 members of the Quality End-of-Life Care Coalition of Canada

• Role of Corporate Canada including the CHPCA Champions Council

• So lets think of TWF as an opportunity and then there is Advance Care Planning
Advance Care Planning in Canada: Current Successes

- Stakeholder engagement and partnerships – with provincial governments, health authorities/agencies, community organizations
- Supporting Communities of Practice/Champions – engaged in education and awareness
- Tools being used by organizations, individuals, professionals
- Community activity on April 16th across Canada
- Research and professional engagement

Advance Care Planning in Canada
La planification préalable des soins au Canada
Speak Up • Parlons-en
Start the conversation about end-of-life care
Dialogue sur les décisions de fin de vie
Flagship Resource: Speak Up Workbook

- Print and online versions – interactive with reflective questions
- Works through the 5 Steps
- For personal use and encourage to give copies to the substitute decision maker, family, healthcare providers
- National, Ontario, Nova Scotia, BC
- Evaluated through research

Advance Care Planning in Canada
La planification préalable des soins au Canada
Suite of Tools for the Public and Professionals
Raising Awareness Through...

- Social media – Facebook, Twitter, YouTube
- Media engagement – Globe & Mail, McLeans, The Current
- Seasonal campaigns
- Blogs, PSAs

Advance Care Planning in Canada
La planification préalable des soins au Canada
Speak Up · Parlons-en
Start the conversation about end-of-life care
Dialogue sur les décisions de fin de vie
Future Challenges

• There is a reluctance of the public and professionals to have the conversation - it’s a hard sell!

• Embarking on a public health approach – ‘Can Advance Care Planning be more like bicycle helmets?’

• Need funding - for the people to do the work
So what about awareness as an opportunity?

Can we recruit Canadians to speak on their behalf
What our new federal government says!
Canadians are looking for real conversations about strengthening end-of-life care and support, including palliative care. It falls on us, as legislators, to act, and that means leading a broad and inclusive discussion with all Canadians

Taken from a letter from the Liberal party dated August 31, 2015
M-456: Pan Canadian Palliative and End-of-Care Strategy

The government should establish a Pan-Canadian Palliative and End-of-life Care Strategy by working with provinces and territories on a flexible, integrated model of palliative care that:
(a) takes into account the geographic, regional, and cultural diversity of urban and rural Canada as well as Canada’s First Nation, Inuit and Métis people;
(b) respects the cultural, spiritual and familial needs of all Canadians; and
(c) has the goal of (i) ensuring all Canadians have access to high quality home-based and hospice palliative end-of-life care, (ii) providing more support for caregivers, (iii) improving the quality and consistency of home and hospice palliative end-of-life care in Canada, (iv) encouraging Canadians to discuss and plan for end-of-life care.

Latest Activity: Decision Made - Agreed To (2014.05.28)
the power of 10

Let’s Talk About Hospice Palliative Care

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs
1. What is hospice palliative care?
2. Does receiving hospice palliative care mean that death is coming soon?
3. How is hospice palliative care different from the health care I am receiving now?
4. What does integrated hospice palliative care mean?
5. Does hospice palliative care also apply to families?
6. What difference will hospice palliative care make?
7. What’s next?

If you would like more information about hospice palliative care services in your area, or help in starting a conversation about hospice palliative care with a loved one, please visit www.chpca.net.
Resources:

the power of 10

LET’S TALK ABOUT HOSPICE PALLIATIVE CARE

ONE OF THE FIVE WAYS to spread an important message is through your social circles, your own sphere of influence. PalaCare Canada’s official theme for 2015 is “The Power of 10—Talk about Hospice Palliative Care.” We urge you to talk to 10 people—friends, family, acquaintances—about the importance of quality hospice palliative care in Canada. Our hope is that these critical messages will spread exponentially, like ripples in a pond, by each of your contacts—whether face-to-face, in-mail, or social media—so the information becomes a conversation starter.

WHAT IS HOSPICE PALLIATIVE CARE?
Hospital palliative care aims to relieve suffering, while improving the quality of life, patients and families.

DOES RECEIVING HOSPICE PALLIATIVE CARE MEAN THAT DEATH IS COMING SOON?
Hospice palliative care is not just for the final days or months of life; it’s care that should begin when a life-threatening condition is diagnosed or when an individual chooses to focus on living with their disease.

DOES INTEGRATED HOSPICE PALLIATIVE CARE MEAN?
An integrated palliative care approach to care is one that focuses on an individual’s need at any given point in time. It can be provided in a hospital, residential hospice, at home, or in small group homes or in another community setting. Personal values, values and needs are considered.

HOW IS HOSPICE PALLIATIVE CARE DIFFERENT FROM THE HEALTH CARE I AM RECEIVING NOW?
Hospice palliative care professionals work with the health team you already have, and together they focus on managing the symptoms of suffering, anxiety, and grief for those living with chronic and life-limiting illnesses.

DOES HOSPICE PALLIATIVE CARE APPLY TO FAMILIES?
Hospice palliative care supports families as they navigate the difficulties that can arise when a loved one is struggling with a life-limiting illness. Through hospice palliative care, families gain a better understanding of their loved one’s wishes, and gain the tools for coping with the illness.

WHAT FACTS WILL HOSPICE PALLIATIVE CARE MAKE?
Hospital palliative care manages pain and symptoms, and teaches the importance of interventions and planning that hospice palliative care encourages. Patients and their family members discuss their care goals, to ensure that their wishes are met, and have a better quality of life.

WHAT’S NEXT?
If you would like more information about hospice palliative care services in your area, or help in starting a conversation about hospice palliative care with someone you know, please visit www.hpc.ca or call 1-800-463-4028. The website for the Canadian Hospice Palliative Care Association offers valuable resources and links.

http://www.hpc.ca
http://www.hospicepalliative.ca
http://www.hospicepalliative.ca
http://www.hpc.ca

the power of 10

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs
A second campaign called “Hospice Palliative Care First” is providing tools for health care educators not working in hospice palliative care.

So what would an Action Plan look like?
An Action Plan

1. We need to continue to promote The Way Forward initiative in order to integrate hospice palliative into the health care system. This is directly related to us not handling chronic care within our acute care system. What does care in the community look like. And how are communities caring – what does a caring community look like. This will be necessary for us to move forward.
An Action Plan

2. Continue to promote advance care planning including Speak Up: Start the conversation around end-of-life care with governments, health care professionals, and all Canadians.

If Canadians don’t want to talk about dying and death then talk about how we want to live our lives right to the end.
An Action Plan

3. A national advocacy campaign clearly articulating what hospice palliative care is, what it does and how important it is for all Canadians. Using campaigns like the Power of Ten and social media we continue to Speak up. Together we can make a difference.
In closing we have come a long way over the last decade but still have a way to go. We have some good opportunities we just have to be strong enough to take them and to speak with one voice together.

So when you leave this conference we ask you to speak to 10 people about HPC and ask them to speak to another 10. **Power of 10!**
Thank you!

Questions?