

Advocacy:  
How can we influence policy  
and funding to embed early  
palliative care in chronic  
diseases



# Definitions

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- Advocacy: from Latin “voc” pertaining to voice and means “speaking for others”. It involves education of public and decision-makers
- Lobbying: attempts to influence policy by communication with a legislative member or staff.

# Palliative care: advocacy and policy milestones

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- 1991 Canadian Hospice Palliative Care Association formed
- 2002-2007 – National strategy for palliative care funded and developed
- 2004 Health Accord – federal money given for home/community care and palliative care
- 2003 Compassionate Care Benefits developed, updated in 2017
- 2007 – Strategy “politically aligned with liberals”. Cancelled
- 2011 Ad-hoc all-party Parliamentary Committee on Palliative and Compassionate Care recommends strategy. Report accepted by vote in parliament
- 2014 Palliative Care Motion 546 by MP Charlie Angus received all party support

# Palliative care: advocacy and policy milestones

- 2015 Liberal Majority Government

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- Budget 2016 No mention of Palliative Care Strategy
- 2016 Health Accord gives money for home care (\$3B but no specifics re palliative care)
- 2017 - Bill C-277 private members bill MP Marilyn Gladu – development of a palliative care framework - passed
- 2017 Health Accord federal funding 1.4B over 10 years for home care/palliative care and mental health – no accountability
- 2018 Framework on Palliative Care in Canada released in December
- 2019 Action Plan on Palliative Care published by Health Canada
- 2021 What has changed? Still calling for full implementation of the framework

# Parliamentary Budget Office

<https://www.pbo-dpb.gc.ca/en/blog/news/BLOG-2021-007--federal-investments-in-palliative-care--investissements-gouvernement-federal-dans-soins-palliatifs>

## *Federal investments in palliative care (2016–17 to date)*

*Table 1*

Category	2016–17	2017–18	2018–19	2019–20	2020–21	Total (\$)
Framework on palliative care			83,087			83,087
Action plan on palliative care				6,163		6,163
General contracts	38,150					38,150
Office of Palliative Care	2,000	3,000	11,046	9,565	7,395	33,006
Funded projects through grants and contributions	868,521	1,839,000	3,165,400	4,501,684	3,192,628	13,567,233
Total	908,671	1,842,000	3,259,533	4,517,412	3,200,023	13,727,639

Source: Health Canada

# Parliamentary Budget Office

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## *Total federal investment in palliative care*

*Table 4*

(\$ thousands)	2017-18	2018-19	2019-20	2020-21	2021-22	Total
Federal investments in palliative care	909	1,842	3,260	4,517	3,200	13,728
Initiatives specific to palliative care in bilateral agreements	11,650	33,070	37,180	39,260	49,380	170,540
<b>TOTAL</b>	<b>12,559</b>	<b>34,912</b>	<b>40,440</b>	<b>43,777</b>	<b>52,580</b>	<b>184,268</b>

Sources: Health Canada and PBO calculations

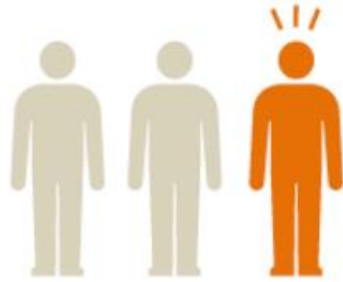
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# Parliamentary Budget Office

- Bilateral health agreements between federal and provincial government
- Only 6 provinces identified palliative care projects that the money would be spent on
- Those 6 provinces' projects would total 170M from 2017-18 to 2021-22
- **“Because health is a provincial jurisdiction, Health Canada does not have the access to, or authority to request, program specific accounting.”**
- To receive bilateral funding the provinces must work with CIHI which has been mandated to develop pan Canadian indicators to measure progress in bilateral agreement areas.
- <https://www.cihi.ca/en/shared-health-priorities>
- No mention of palliative care. Only indicators relating to pc were wait time for home care services while in hospital and death at home and caregiver distress

**96%** of individuals receiving long-term home care have an **unpaid caregiver**



More than **1** in **3** of these caregivers are **distressed**

(Source: CIHI, 2019)

Caregivers in distress spend the **equivalent of a full-time job providing care**

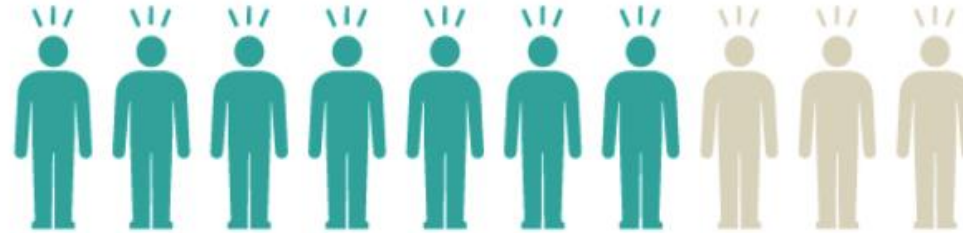
Average **37** hours per week

This is **2x** the hours provided by caregivers who are **not distressed**



(Source: CIHI, 2019)

**7 in 10** caregivers in distress care for someone who needs **substantial** help in at least one personal care activity





# Cost effectiveness of palliative care

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Multiple studies documenting reduced symptom burden, improved satisfaction with care, improved quality of life, lengthening of life

Meta-review of 10 economic analysis of acute care palliative care consultation teams vs usual care

Consistent reduction in hospital costs by 9-25%

One study estimated 32% reduction in all health care costs in the 6 months following admission

Future research on costs outside hospital, costs other than health care, time expended by the patient, unpaid time spent by caregivers

- May et al. J Pall Med 2014

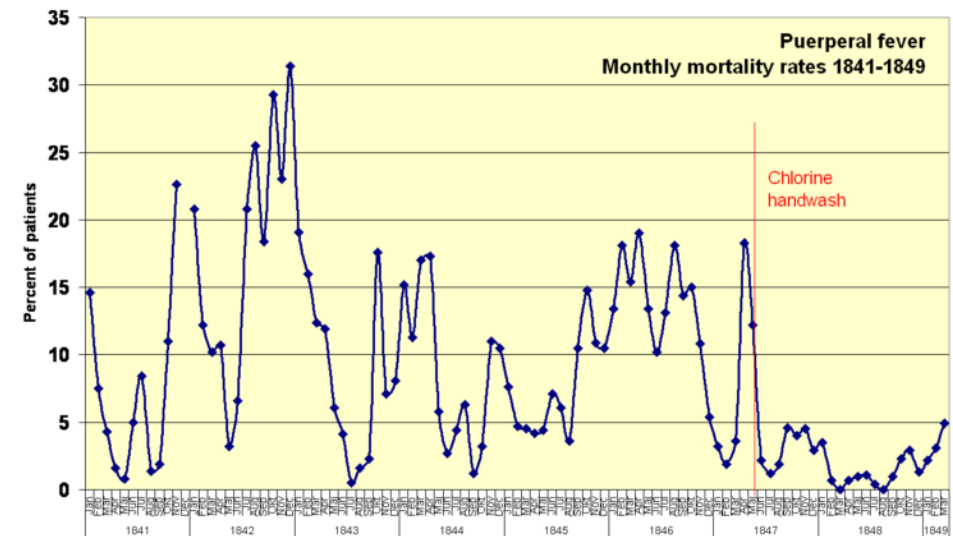
# The Semmelweis reflex

Dr. Ignaz Semmelweis demonstrated in 1847 that hand washing could reduce the risk of “childbed fever”

It took more than 30 years for his work to be accepted

Handwashing did not become routine until the 1880s

rejection of new knowledge because it contradicts entrenched norms, beliefs, or paradigms



# Preventing death

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Cardiopulmonary resuscitation (CPR) was first reported in 1960 after a study was done on 20 post-operative patients

By 1966 was classified as a “universal emergency procedure” in acute care hospitals for any patient who died

- Standards for cardiopulmonary resuscitation (CPR) and emergency cardiac care (ECC). JAMA 1966; 198: 372-379.

Preventing death is very important in medicine.....

# 4 Stages of Development of a Palliative Care Culture

- Denial – palliative care is not needed or useful in our care
- Palliphobia – the need is realized but the solution (changing culture) inspires fear
- Pallilalia – decision/policy makers speak highly of palliative care and its importance but no changes in culture or care are made
- Palli-activeness – the funding/policy/decision-making aligns and supports the change in culture to provide palliative care
  - Bruera, E. J of Palliative Care 2004

# The official curriculum of health care

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Patient-centered care: care is centered around the needs of the patient – body, mind and spirit

Informed consent

The right person, in the right place getting the right service

Cradle to grave

We work together in teams

Effective and efficient care

Universal coverage of health care

# Hidden Curriculum

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attitudes and values conveyed, most often in an implicit and tacit fashion, sometimes unintentionally, via the health care structures, practices, and culture.

may be supportive of or contrary to the formal policy

the culture of medicine is not only defined by what healthcare providers do, say, feel, and think, but also by what they do *not* do, say, feel, or think.

# The hidden curriculum of health care

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Prevention of death is our most important work

Death is the failure of medical care – not a natural process

Dying is a hidden process on the wards and in the hospital

- how do dead patients leave the hospital?
- daily rounds offers discharge or transfer as an outcome – but not death
- “They didn’t die on my shift”
- Did I do something wrong?

# The hidden curriculum of health care

a physician must be thorough, never miss a diagnosis (even if it is not relevant to the patient's overall care or outcome), and maintain a focus on all data about a disease trajectory (even if this merely involves monitoring failing organs).

organ-focused care is common

soft skills - communication not as richly rewarded as technical skills and therefore technical skills more important

research in preventing death with technology (attracts funding and fame) is preferred to all other

more technology and less care is better than less technology and more care  
money determines what we do more than we would like to admit



# Mental Health Advocacy in Canada

- “mental hygiene clinic” at the Toronto Juvenile Court — the first in Canada.

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- early psychiatric treatment for adults in the Out-Patients Department of the Toronto General Hospital. This was the first community mental health clinic in Canada.
- In Canada, Dr. Clarence M. Hincks established a mental hygiene clinic at the Toronto Juvenile Court — the first in Canada.
- Canadian Mental Health Association started 1918
- 1948, as part of the National Health Grants Program, the federal government instituted a Mental Health Grant to assist provinces in developing adequate facilities for the mentally ill.
- 1963 “More for the Mind” (a CMHA document) — “mental illness should be dealt with in the same organizational, administrative and professional framework as physical illness.”
- First effective psychiatric meds developed in 1950s and 1960s

# Mental Health Advocacy in Canada

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1983 public awareness campaign: “My Dad” (combination of TV, radio, magazine and newspaper ads)

- ran for a limited time each year until 1987.
- theme “A Caring Community Is the Answer” the campaign provided a method of increased awareness of mental illness and a shift in attitude towards public support.

2010 Bell – Let’s Talk Campaign – 5 cents from each text/tweet on Let’s Talk Day is given to Mental Health Concerns

- Mental health champions: Howie Mandel, Clara Hughes, Serena Ryder, Mary Walsh, and Michael Landsberg – public awareness campaign
- Campaign changes according to trends – Race and Mental Health
- 2020, Bell extension of the Bell Let’s Talk mental health initiative for a further 5 years and an increase in Bell’s total funding commitment for Canadian mental health to at least \$155 million.



# WHO Roadmap for Palliative Care Development

- Callaway, Connor, Foley
  - <https://www.jpsmjournal.com/action/showPdf?pii=S0885-3924%2817%2930374-3>
- Having national champions – key
- Education/awareness of the public: media campaigns, videos, flash mobs, posters etc...must be a continuous process
- Some countries worked with Human Rights Watch to highlight the right to palliative care and symptom relief
- <https://www.opensocietyfoundations.org/publications/palliative-care-human-right-fact-sheet>

# Top Ten Tips on Evidence-based Advocacy

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1. Educating stakeholders and public is something we are positioned to do well.
2. Consensus based definition of palliative care as well as what we are trying to achieve.
3. Be ready to explain the value of palliative care.
4. Advocate for pc as a component of the right to health care
5. Reference International Law, Multilateral conventions etc that call for universal access to PC.
6. Quantify the scope of unmet needs & identify policy gaps
7. Participate in organizations that advocate for PC
8. Embed advocacy in training and professional development.
9. Know the data showing that PC provision can address social injustice and health inequities
10. Expand influence by presenting at Clinical Conferences and Forums outside of PC and specialty

Journal of Palliative Medicine 2021 DOI: 10.1089/jpm.2021.0182