



PARLIAMENTARY COMMITTEE ON PALLIATIVE AND  
COMPASSIONATE CARE

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November 26, 2010

Meeting with Dr. Jose Pereira: Government Lobby

10:15 AM

MPs Present:

Kelly Block MP

Harold Albrecht MP

Rod Bruinooge MP

Maurice Vellacott MP

THESE NOTES ARE  
FURNISHED BY THE  
P.C.P.C.C. AND HAVE  
NOT BEEN REVIEWED  
BY PALLIUM PROJECT  
PRIOR TO RECEIPT

Noted: Dr. Pereira is **not a registered lobbyist**

**Harold Albrecht** asked Dr. Pereira to speak to the apparent divide between the Medical Model and the Care model in Palliative care.

Dr. Pereira notes that Palliative care doctors are slightly insulted by the distinction between a medical and care model. In reality Palliative care doctors look at the needs of the whole patient, practicing total care, physical, emotional, spiritual, and psychological. "Total Patient Care" In some countries a false dichotomy developed between a Hospice movement which portrayed itself as a "Care model" and a Palliative care movement which the Hospice people portrayed as a "medical model". Medicalization **does** occur in hospitals i.e. cancer wards, where for example chemotherapy is given even when it has become futile medical treatment. Palliative care, on the other hand, does know the difference between cure and care.

Palliative care is about palliating a range of symptoms:

Pain

Nausea

Fatigue

Depression

Anxiety

Delerium

Dyspnoea (shortness of breath)

Dr Pereira noted that we are facing a major societal crisis which will effect

- a) Health care
- b) Social system
- c) Economy

With an aging population we need careful planning because everyone is affected, most especially by death and the end-of-life trajectory. It costs \$20,000 per month to look after a dying person, something due mainly to improper utilization of health care resources. We need to plan how to utilize our resources more adequately.

**Kelly Block** notes that a number of ministers and MPs always are arguing that since health care is a provincial issue the Federal level of Government should keep out. Kelly wonders how best to articulate a Federal role in these issues.

Dr. Jose notes that there is the need for a unified national approach, basic national standards, so that all Canadians can expect at least basically the same level of care anywhere in the country. This of course comes through the kind of leadership that only the Federal Government can offer.

**The role of the Federal Government is leadership.** i) Strategy ii) Palliative and End of life Secretariat

Basic Federal Standards

- a) All citizens should have access to hospice/Palliative care

In Ontario for example only 40% of direct costs of hospice care is covered by public health funds. Hospice is not seen as core health care. As a result many of our residential hospices are finding most of their time taken up with fundraising, and many are running at or near bankruptcy.

The Federal government could have a standard that 80% even 100% of costs to run hospices would be funded from health care revenue.

This of course would ultimately save money! The Champlain Regional LNN for example is working on a hospice plan. It costs \$1200 per day for a person to die in the hospital. It costs

\$380-400 per day to die in hospice. Yet 70% plus of people in Ontario are still dying in the hospital. This is both bad care and bad use of health care resources.

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In Alberta on the other hand only 25-30% of cancer patients still die in the hospital. In Ontario 70-80% of Cancer patients die in hospital. This is because we don't have enough hospice and home care.

**Recommendation:**

We need a Pan Canadian Institute to look at Palliative and End of Life Care. It would be a multi disciplinary institute with economists, demographers, sociologists, doctors, administrators etc. which would provide an in depth response/ interdisciplinary research, as to how to best transform health care so as to provide adequate care for the coming age wave generation.

Because at present we put the dying in inappropriate care:

- i) They are getting worse care
- ii) They are getting very expensive care

We need to do serious research on the costs of aging across the country. **It is the Federal role to provide national leadership.**

Present problems:

- a) Example of man from the Ontario border of Northern Quebec dying of Cancer. His family were across the border in Quebec, but it proved impossible to get him from Ontario to Quebec so he could die near his family. (3 month waiting period to transfer care from Province to Province).
- b) Aboriginal Palliative care—very much lacking! This is Federal jurisdiction “They move the dying away from our communities and we never see them again”. Native elder (Northern Ontario)
- c) Need to inform people about dying. Need a major national education project on death and dying, appropriate care, nutrition and hydration, inappropriate treatment etc.
- d) Need national standards for necessary drugs needed so people can die comfortably, so that they are available across the country. E.g. low dose Phentonol not covered in Ontario, but it really is useful for giving people at end of life adequate pain control.

We need a **national strategy**! Even Georgia(former Soviet Union) and Poland now have national Palliative care strategies. We need a **secretariat** to coordinate activities between the levels of government, the stakeholders etc. Canada once led the world in Palliative care and is rapidly falling behind for lack of coordination and leadership.

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PEREIRA BRIEFING  
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**Pallium Book** Original draft written by Dr. Pereira, peer reviewed by 12 leading experts from all aspects of palliative care, and collaboratively re written. Now affectionately known as the "bible of palliative care"

Proof of what collaborative effort can accomplish. The Pallium book was accomplished, however, with funding from the government (printing and layout costs) through the Palliative care secretariat and National Strategy.

NOT CORRECT  
P.P.P. PUBLICATION LAYOUT &  
PRINTING ON A CO-OPERATIVE,

Kelly mentioned that Dr. Pereira should speak with Ted Menzies Parliamentary Secretary to the Minister of Finance. (Send Dr. Pereira Ted Menzies contact info.)

COST  
RECOVERY  
MODEL.

2003-2008 CIHR Palliative and End-of-Life Care research funding. **This Galvanized Palliative care research!** Lasted 5 years and then stopped. It is very difficult to find palliative care research funding today. Not perceived as "sexy" in the way new cancer drug or heart drug research is. Dr. Pereira notes that Canada could be at the forefront of Delirium research, but again no funding is available. **We need CIHR funding sources for Palliative and End-of-Life care research!**

MJ Ahum  
notation

Dr. Pereira noted that the original Palliative care push encompassed:

National Strategy

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Secretariat

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Palliative care research funding

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Compassionate care benefit

**Promised to forward a copy of Megan Leslie's suicide Prevention Strategy Bill to:  
Rod, Maurice, Kelly and Harold**

Need better home care! Conrad Festband in Alberta has shown that money saved through proper home and Palliative care.