

*Alberta Cancer Board*  
***HOSPICE PALLIATIVE CARE NETWORK***

***PROVINCIAL FRAMEWORK***

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**October 2003**

# The Alberta Cancer Board Hospice Palliative Care Network Provincial Framework<sup>1</sup>

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ISBN: 1-894809-14-9

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**Attribution/Citation Statement**

Paquin M-J. (2003). *The Alberta Cancer Board Hospice Palliative Care Network – Provincial framework*. Edmonton, AB: Alberta Cancer Board.

Funding for the Hospice Palliative Care Network is provided by the Alberta Cancer Foundation.

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<sup>1</sup> The *Supportive Care- Provincial Framework* developed by Cancer Care Ontario provided guidance for the development of this framework.

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## Introduction

The Palliative Care Network Initiative (PCNI) was created by the Alberta Cancer Board (with funding from the Alberta Cancer Foundation) in 1998 to contribute to the vision of providing equitable access to palliative care services for people living or affected by cancer in Alberta. On the basis of a needs assessment done at that time, three goals were identified for the PCNI. These related to ensuring use of common language, developing standards of practice in collaboration with health authorities, and supporting the development of seamless palliative services delivery. Between 1998 and 2003, many activities have been undertaken and are described in a paper titled *The Palliative Care Network Initiative - Looking back; Moving forward* (Paquin & Pereira, 2003).

In February 2003, the Palliative Care Network Initiative held a Strategic Planning Workshop to seek valued input from 17 stakeholders across the province. Highlights and findings from the workshop are outlined in a paper titled *Palliative Care Network Initiative: Looking forward-Report from a workshop held February 21, 2003* (Birdsell, 2003). The group values the role of the PCNI and sees it as an evolving organizational structure. Aligned with this vision, the group strongly recommended dropping the word “initiative” from the title of the PCNI and maintaining the “Network” approach. Building on these suggestions, the PCNI will be operated under the name *Hospice Palliative Care<sup>2</sup> Network (HPCN)*, effective November 1, 2003.

This document outlines the foundation of the HPCN. The HPCN Provincial Framework is based on the national norms of hospice palliative care practice developed by the Canadian Hospice Palliative Care Association Model (Ferris et al., 2002) was used.

## Purpose

The purpose of the ACB Hospice Palliative Care Network is:

- To improve access and enhance integration of hospice palliative care in the province so that services that are needed are available timely to cancer patients/families.

Therefore the ACB Hospice Palliative Care Network develops working/collaborative partnership with all people/organizations who provide hospice palliative care to people living with cancer and their families and plans activities (see Hospice Palliative Care Network Annual Work Plan) that:

- address the expectations/needs of patients/families/caregivers;
- influence hospice palliative care programs/services planning, development, implementation, and evaluation.

## Mission

As an ACB initiative, the Hospice Palliative Care Network (HPCN) reflects the organization’s mission (Alberta Cancer Board, 2002):

“To reduce the burden of cancer through prevention, screening, diagnosis, treatment, palliation, education, and research.”

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<sup>2</sup> Within the consultation process of developing national norms of hospice palliative care practice, the words « hospice » and « palliative care » were coined. Therefore, hospice palliative care is the term nationally accepted and replaces “palliative care”. The renaming of PCNI is aligned with this new terminology.

## **Vision for Hospice Palliative Care in Alberta**

The HPCN works to achieve the following vision for hospice palliative care in Alberta:

- Equitable access to hospice palliative care for individuals living with cancer and their family members regardless of where they live in the province and how they enter the health/cancer care system.

## **Values**

The HPCN is committed to the core values of hospice palliative care defined by the Canadian Hospice Palliative Care Association (Ferris *et al.*, 2002):

1. The intrinsic value of each person as an autonomous and unique individual.
2. The value of life, the natural process of death, and the fact that both provide the opportunities for personal growth and self-actualization.
3. The need to address patients' and families' suffering, expectations, needs, hopes and fears.
4. Care is only provided when the patient and/or family is prepared to accept it.
5. Care is guided by the quality of life as defined by the individual.
6. Caregivers enter into a therapeutic relationship with patients and families based on dignity and integrity.
7. A unified response to suffering strengthens communities.

## **Definition of Hospice Palliative Care**

Hospice palliative care aims to relieve suffering and improving the quality of life for persons who are living with or dying from a life-threatening illness or are bereaved (Ferris *et al.*, 2002).

The delivery of hospice palliative care involves a wide range of individuals and agencies. For the individual who is living with cancer to experience effective hospice palliative care, the system for delivering the care must be coordinated and comprehensive. The full range of stakeholders, both within institutional settings and community settings, need to work collaboratively. The HPCN embraces this principle of inclusiveness.

## **Hospice Palliative Care Standards for Patient/Family Care and Program Planning**

In 2002, the Canadian Hospice Palliative Care Association (CHPCA) published its *Model to Guide Hospice Palliative Care Based on National Principles and Norms of Practice* (Ferris *et al.*, 2002). The CHPCA Model proposes the use of “norms” rather than “standards” of practice to ensure that all Canadians have access to consistent, high quality care that can relieve suffering and improve quality of life.

There are two main aspects of the CHPCA Model to guide hospice palliative care: 1) the delivery of patient and family care and 2) the development and function of an organization. The interrelationship between patient and family care and organizational function is illustrated by the integrated “Square of Care and Organization” (Figure 1).

**Figure 1: The CHPCA Square of Care and Organization<sup>3</sup>**

		Process of Providing Care							
		Assessment	Information Sharing	Decision-making	Care Planning	Care Delivery	Confirmation		
<b>Common Issues</b>	Disease Management							<b>Principal Functions</b>	
	Physical								
	Psychological								
	Social	<b>Patient and Family Care</b>							
	Spiritual								
	Practical								
	End of life/ Death Management								
	Loss, Grief								
		Financial	Human	Informational	Physical	Community			
		<b>Resources</b>							

It is important for the HPCN to develop the capacity of the cancer clinics/health regions/community organizations to provide access to hospice palliative care aligned with the 2002 CHPCA Model.

## **Resources of the ACB Hospice Palliative Care Network**

The CHPCA Model suggests that hospice palliative care programs/organizations develop and maintain five key resources (financial, human, informational, physical, and community). The HPCN integrates these resources within its program.

### **a. Financial Resources**

The HPCN is funded on an annual basis by the Alberta Cancer Foundation. The funding allows the availability of other key resources listed below.

### **b. Human Resources**

The HPCN team includes a Medical Advisor, a Provincial Coordinator and a Program Assistant. Volunteers and students join the HPCN Team on an ad hoc basis.

The Provincial Coordinator provides provincial leadership and coordination of hospice palliative care activities for the Medical Affairs and Community Oncology (MACO) Division with the Alberta Cancer Board. The individual serves as a resource for the cancer centres/health regions and other organizations. S/he ensures that the CHPCA Model is known and encourages collaboration among the hospice palliative care stakeholders/caregivers (especially in matters of program planning & development, education and quality measurement).

<sup>3</sup> Figure excerpted from: Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, & West P. (2002). *A model to guide hospice palliative care*. Ottawa, ON: Canadian Hospice Palliative Care Association, p. 55.

**c. Information Resources**

The HPCN accesses hospice palliative care information/resources through the Cross Cancer Institute and Tom Baker Cancer Centre libraries (e.g., books, journals) and the richness of materials developed by cancer centres/health regions/community organizations.

The HPCN provides informational resources to stakeholders/caregivers such as the *Alberta Palliative Care Resource* (Pereira & Bruera, 2001) and other materials developed by the Network (e.g., Brochure, Info Sheet, etc.). The HPCN communicates information about hospice palliative care in the province through the maintenance of a provincial hospice palliative care web site (<http://www.albertapalliative.net>), the development/dissemination of a provincial directory of resources, and information sharing to HPCN email users.

**d. Physical Resources**

The ACB MACO Division oversees the HPCN Program. It provides the program with access to all resources within the ACB (e.g., human resource & finance department), including access to an office, communication and information technology systems (e.g., telephone, computer, printer, network system, email, internet access), and supplies.

**e. Community Resources**

The HPCN interacts/collaborates with a vast “Hospice Palliative Care Community” in Alberta (see Figure 2) that continuously evolves according to the expectations/needs of patients/families/caregivers. Therefore, Figure 2 may not accurately reflects the “Community” but it shows that all sectors (health, education, research, voluntary) contribute to hospice palliative care in Alberta.

**Figure 2: The Hospice Palliative Care Community in Alberta**

Health		Education	Research	Voluntary
Provincial	Regional			
<ul style="list-style-type: none"> <li>• Alberta Health and Wellness</li> <li>• ACB Palliative Care Network Initiative (PCNI); Cross Cancer Institute and Tom Baker Cancer Centre</li> </ul>	<ul style="list-style-type: none"> <li>• Acute care</li> <li>• Home care</li> <li>• Hospice</li> <li>• Long-term care</li> <li>• Respite care</li> <li>• Bereavement</li> <li>• Pediatric palliative care</li> </ul>	<ul style="list-style-type: none"> <li>• Pallium</li> <li>• Centre for Distance Learning in Palliative Care</li> <li>• PCA &amp; PCNI Train-the-trainer workshop</li> <li>• Tertiary Program Annual Conference (Spring: Calgary; Fall: Edmonton)</li> <li>• Rural Palliative Care Conference</li> <li>• Grant MacEwan Community College</li> <li>• University of Alberta</li> <li>• University of Calgary</li> </ul>	<ul style="list-style-type: none"> <li>• Palliative Care Research Initiative</li> <li>• University of Alberta</li> <li>• University of Calgary</li> <li>• Alberta Heritage Foundation for Medical Research</li> </ul>	<ul style="list-style-type: none"> <li>• Palliative Care Association of Alberta (PCAA)</li> <li>• Palliative Care Council or Society (rural)</li> <li>• Calgary Hospice Society</li> <li>• Pilgrim’s Society</li> <li>• Red Deer Hospice Society</li> <li>• Canadian Cancer Society, AB/NWT</li> </ul>

**Principal Functions of the ACB Hospice Palliative Care Network**

The CHPCA Model suggests that hospice palliative care programs/organizations implement five principal functions (governance and administration, planning, operations, quality management (evaluation), and communications/marketing community). The HPCN incorporates these functions within its program.

**a. Governance and Administration**

The MACO Division with the Alberta Cancer Board oversees the operation of the HPCN. It provides guidance to the HPCN development and function. It also reports HPCN activities/realizations to the ACB Board of Directors and the Alberta Cancer Foundation.

**b. Planning**

The development of the HPCN is congruent with the overall mission and vision statements, the strategic plan and business plan of the ACB and the MACO Division. The HPCN validates its purpose and work plan with hospice palliative care stakeholders/caregivers.

**c. Operations**

The HPCN uses the CHPCA Norms of practice to guide the development of its program and activities. It uses the best available hospice palliative care guidelines or tools to guide the development of policies and procedures, data collection and evaluation.

**d. Quality Management (Evaluation)**

The HPCN participates in the ACB accreditation review. The HPCN documents the outcome and resource utilization data for its program.

**e. Communications/Marketing**

The HPCN establishes internal and external communication process to disseminate information about its program and other hospice palliative care initiatives or resources.

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