

Applying A Model to Guide Hospice Palliative Care

**An Essential Companion Toolkit
for Planners, Policy Makers,
Caregivers, Educators, Managers,
Administrators and Researchers.**

**To be used in conjunction with:
*A Model to Guide Hospice Palliative Care:
Based on National Principles and
Norms of Practice***



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

2005



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Production of this document has been made possible, in part, by a financial contribution from the Primary Health Care Transition Fund (PHCTF), Health Canada, through the Pallium Integrated Care Capacity Building Initiative. The views expressed herein do not necessarily represent the official policies of Health Canada.

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***Additional Copies of A Model to Guide Hospice Palliative Care**

Copies of *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* can be obtained from the Canadian Hospice Palliative Care Association national office. Contact information can be found on page 2 of this tool-kit.

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ISBN: 1-896495-13-3

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Acknowledgements

The Canadian Hospice Palliative Care Association acknowledges the contribution of the following persons and/or organizations towards the development of this resource.

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Table of Contents

Background	5
What is A Model to Guide Hospice Palliative Care?	5
How to Use the Model	5
About this Toolkit.....	5
1. Getting Started.....	7
The Model.....	8
Conceptual Frameworks	9
Square of Care	10
Square of Organization	10
Square of Care and Organization.....	11
Program or Service Audit	12
Process Models to Assist with Application of the CHPCA Model	12
2. Using the Model to Guide Policy	13
2.1 Developing Policy	13
3. Using the Model to Guide Planning	15
3.1 Planning a legacy project.....	15
3.2 Developing a service delivery model for rural and remote areas	16
3.4 Planning a Rural Residential Hospice	17
4. Using the Model to Strengthen Clinical Programs and Services.....	20
4.1 Developing and Evaluating a Clinical Tool.....	20
4.2 Developing Clinical Guidelines.....	21
4.3 Developing Referral Criteria	25
4.4 Assessing Quality/Checking Current Practices Against the Norms	26
4.5 Building Partnerships.....	27
4.6 Evaluating/Accrediting a Hospice Palliative Care Program	28
5. Using the Model to Guide Education	29
5.1 Assessing Competencies and Developing Learning Plans	29
5.2 Developing Orientation and Education Programs and Identifying Education Priorities	30
5.3 Developing Best Practices for Volunteer Services	31
5.4 Developing Education Activities for Courses, Workshops and in-service Training	32
5.5 Planning a Conference	32
6. Using the Model to Manage a Hospice Palliative Care Program, Service or Organization	34
7. Summary	36

Background

Hospice palliative care is care that aims to relieve suffering and improve the quality of living and dying.

What is A Model to Guide Hospice Palliative Care?

In March 2002, the Canadian Hospice Palliative Care Association published *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice (the Model)*. The Model sets out principles and norms of practice for hospice palliative care, which have been endorsed by hospice palliative care caregivers and organizations across the country.

The norms describe the “usual” practice for hospice palliative care. Caregivers and organizations use the norms to set their own standards of practice.

The purpose of the Model is to create a shared vision for hospice palliative care in Canada and encourage a consistent approach to providing care and organizing services. It provides a common language, values and principles that people can use to guide their work. This, in turn, will help ensure that all Canadians have access to consistent, high quality hospice palliative care. Canada is the first country to have developed this specific kind of consensus-based roadmap or guide for hospice palliative care.

How to Use the Model

The Model establishes the goalposts that all hospice palliative care programs and services in Canada should be striving to reach, and provides a roadmap to help them get there. Organizations are **not** expected to implement the complete Model across their hospice palliative care programs, services and organizations **all at once**. They are expected to start where they are and gradually, over time, use the Model to shape and strengthen all aspects of their practice. It is strongly suggested that organizations select tangible portions of their current program when beginning this process so the process does not overwhelm team members. This tactic will ensure that agreed upon goals and outcomes are achieved.

Organizations that have used the Model describe it as a catalyst for reviewing and improving practice, or as a touchstone that they continually use to ensure they are achieving their goals and making progress in fulfilling their mission. They stress that the Model is not a recipe: it does not tell hospice palliative care programs and services what to do or how to do it; the Model describes the desired practice they should be trying to achieve. It's up to each organization to figure out the best way to get there.

About this Toolkit

This toolkit is not a stand-alone document. It is intended to be used **in conjunction with** the *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*, and makes references to specific pages in the Model throughout this toolkit. The toolkit provides examples of how the Model can be used to guide all aspects of

planning and delivering hospice palliative care services. Copies of *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* can be obtained from the Canadian Hospice Palliative Care Association national office. Contact information can be found on page 2 of this toolkit.

1. Getting Started

The first step in applying the Model – whether it is being used to plan a program, evaluate a service, or develop education programs – is understanding the *basic definitions and concepts* underlying the Model (pp 17-23).

A core construct of the Model are the **Values** and **Guiding Principles** that were developed and agreed upon through a national consensus-based process. The CHPCA considers these values and guiding principles to be at the core of all hospice palliative care programs and services in Canada. All programs and services are encouraged to consider these carefully as they develop their own local program or service model.

It is important that everyone involved in applying the Model have an opportunity to discuss the **definitions, values** and **guiding principles**, and to agree that these should guide their work. As a group, they may localize these values and guiding principles, and identify others they would like to see reflected in their practice. The values and principles can also be used to help explain the need for change to others who may be affected by the change. The key is to achieve consensus on how to apply the values and guiding principles of the Model for your local program or service.

The group may then develop a plainly worded local vision statement that reflects the agreed upon local adaptation of the values and guiding principles. The vision statement can be used to guide the development of programs, services and the organization, and to help plan communications (see p 42).

Values

All hospice palliative care activities recognize and support the following values:

V1. The intrinsic value of each person as an autonomous and unique individual.

V2. The value of life, the natural process of death, and the fact that both provide opportunities for growth and self-actualization.

V3. The need to address patients' and families' suffering, expectations, needs, hopes and fears.

V4. Care is only provided when the patient and/or family is prepared to accept it.

V5. Care is guided by quality of life as defined by the individual.

V6. Caregivers enter into a therapeutic relationship with patients and families based on dignity and integrity.

V7. A unified response to suffering strengthens communities.

Guiding Principles

All hospice palliative care activities recognize and support the following principles:

GP1. Patient / Family Focused

GP2. High Quality

GP3. Safe and Effective

GP4. Accessible

GP5. Adequately Resourced

GP6. Collaborative

GP7. Knowledge-Based

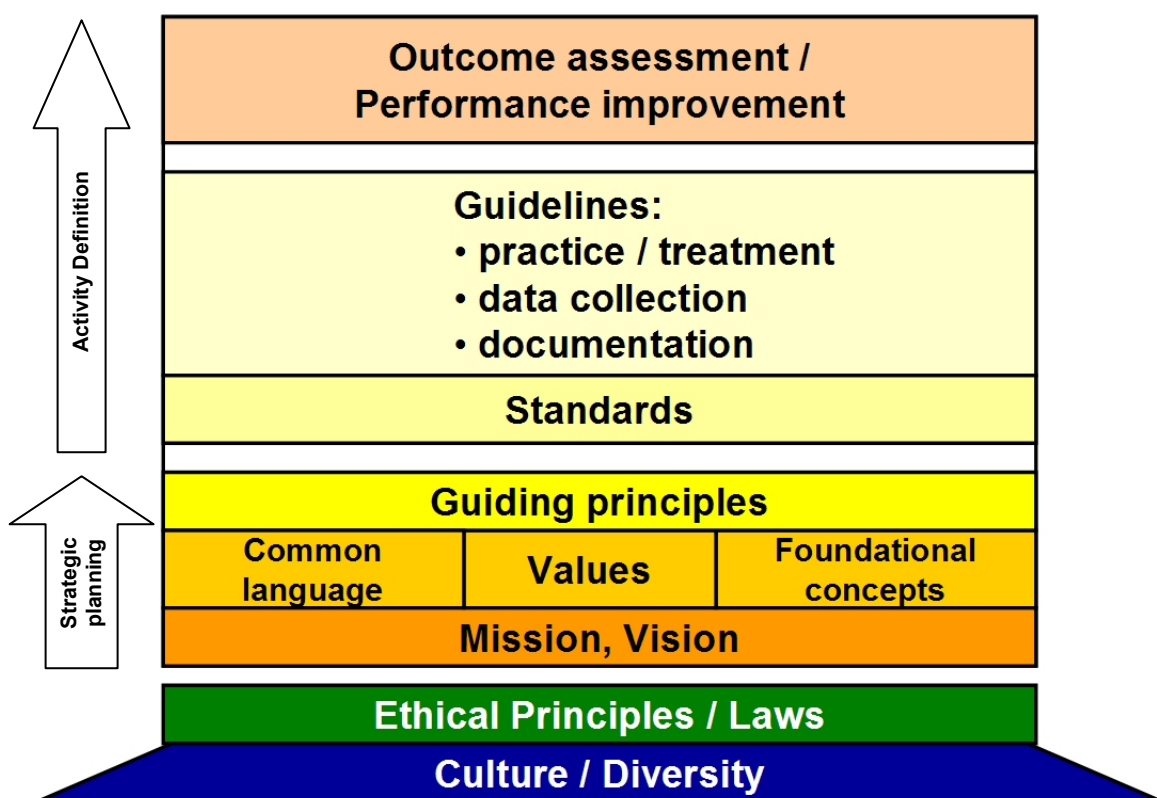
GP8. Advocacy-Based

GP9. Research-Based

The Model

The following figure illustrates how aspects of the Model fit together. While the concepts illustrated below were all included in *A Model to Guide Hospice Palliative Care*, this figure illustrates how the concepts are integrated.

By building each component of the Model carefully, from the bottom up, without missing key details, hospice palliative care organizations will set the stage to provide consistent, high quality care to all of their patients, families and customers.



Every hospice palliative care program/service is contextual, i.e. it is built within a community. While there may be many similarities from one community to the next, each community has its own culture and customs, diversity, ethical principles and laws that guide the behaviors of all the people living and working within that community. These four characteristics form the foundation on which any program or service within that community is built.

As a group of people come together to form an organization that will carry out one or more activities, for example provide hospice palliative care, they must first negotiate priorities, identify key needs to be addressed and then define the processes they will use to carry out each of the activities that are part of their business. This will often be undertaken as a strategic planning process.

Integral to strategic planning is definition of the organization's:

1. Mission, ie, what it will do, including its principal activities
2. Vision, ie, what it hopes to achieve in the future
3. Definition of a common language that will be used when communicating from one person to another, ie, the lexicon in *A Model to Guide Hospice Palliative Care*
4. Values that will guide all communication and interactions between members of the organization, and with other people and organizations in the community
5. Foundational concepts, even beliefs, that are at the root of all activities, that every person in a hospice palliative care program/service is a leader, teacher and a change agent (to be effective, the organization needs to ensure that every person has these skills so they can apply them daily).
6. Principles, or fundamental truths, guiding all activities within the organization

As strategic priorities and direction are endorsed and supported, members of the organization tend to negotiate, define and agree to the processes that will guide their activities, including:

1. both process and outcome standards they hope to achieve
2. guidelines that recommend:
 - a. preferred approaches to practice when conducting a specific activity
 - b. how specific treatments will be delivered
 - c. what data will be collected
 - d. how activities will be documented
3. both process and impact measures to be followed, and the outcome measures associated with both process and impact measures
4. the performance improvement process to be implemented for each activity.

Ideally, to get maximal buy-in and implementation, leaders will use a consensus-building process to undertake their strategic planning and define the processes for each of their principal activities.

Conceptual Frameworks

It is also important to understand the conceptual frameworks -- *the square of care and square of organization* – and how to use them.

Square of Care

The Square of Care describes the six essential steps in the process of providing care: assessment, information sharing, decision making, care planning, care delivery and confirmation, and illustrates that they apply to the issues (or domains) that patients and families commonly face.

		Process of Providing Care					
		Assessment	Information Sharing	Decision-making	Care Planning	Care Delivery	Confirmation
Common Issues	Disease Management						
	Physical						
	Psychological						
	Social						
	Spiritual						
	Practical						
	End of life/ Death Management						
	Loss, Grief						

Patient and Family Care

Square of Organization

The Square of Organization describes the functions of a hospice palliative care program, service or organization and the resources required to function and provide care in a safe, ethical, responsive and compassionate manner.

					Governance & Administration	Principal Functions
					Planning	
					Operations	
					Quality Management	
					Communications, Marketing	
Financial	Human	Informational	Physical	Community	Resources	
Resources						

Principal Activities

Resources

Square of Care and Organization

When the two squares are combined, they illustrate all aspects of a palliative care program, service or organization. The patient and family are at the centre of the combined square, and their needs determine the issues to be addressed, the care required and the functions and resources to provide care.

		Process of Providing Care							
		Assessment	Information Sharing	Decision-making	Care Planning	Care Delivery	Confirmation		
Common Issues	Disease Management							Governance & Administration Planning Operations Quality Management Communications, Marketing	Principal Functions
	Physical								
	Psychological								
	Social	Patient and Family Care							
	Spiritual								
	Practical								
	End of life/ Death Management								
	Loss, Grief								
		Financial	Human	Informational	Physical	Community			
		Resources							

With the Square of Care and Organization, individuals and organization can identify the domains of care, the steps of providing care, the organizational functions and the resources affected by an activity. Some key questions to ask in applying the square of care and organization are:

- what issues or domains will the project/program/activity address?
- which steps in the process of providing care are involved?
- which functions of the organization are affected?
- what resources are required?
- who needs to be *involved* in the process of planning and decision making?
- who needs to be *consulted* in the process of planning and decision making?

For example, an organization using the Model to develop a new hospice palliative care program or service would need to address all the elements in the square of care and organization, while a caregiver using the Model to develop a social activity for patients would address only those that apply (e.g., the psychological, social and spiritual domains; assessment, information sharing and decision-making aspects of providing care; and the human, financial and physical resources required).

Program or Service Audit

Before moving forward it is important for organizations to consider applying the Model to their current program or service by way of a Program or Service Audit. Taking time to use the Square of Care and Square of Organization to map out the programs and services already in place, as well as available and/or needed resources provides important early planning and consensus-building benefits. It validates the degree of alignment between the current organization and the Model, it provides a framework for assessing how much of the Model elements are already in place, and sets the stage for positive change.

Process Models to Assist with Application of the CHPCA Model

Many health care organizations are familiar with using planning and development models (such as a “Logic Model”) when conducting program development. The CHPCA Model is essentially a content model (focused on the specific content of the program or service) rather than a planning model (how the program or service will be implemented). Organizations are therefore encouraged to utilize existing tools and planning models when moving forward with the application of the Model to their new or existing hospice palliative care program or service.

2. Using the Model to Guide Policy

The Model can be used to promote laws, regulations and policies that facilitate rather than obstruct the provision of hospice palliative care. Through policies that reflect the norms, hospice palliative care programs, services and organizations can set certain standard expectations for their activities.

2.1 Developing Policy

A provincial cancer agency in collaboration with regional hospice palliative care partners and other stakeholders used the Model to define a strategic alliance for promoting effective hospice palliative care policy for the province.

Goals:

- To promote a more consistent approach to hospice palliative care in the province.
- To ensure all parts of the province have the same access to hospice palliative care expertise.
- To help hospice palliative care stakeholders innovate, share information and work together.

Components of the Model

Core values (page 19)

Guiding principles (page 19)

Square of care and organization (page 55)

Who's Involved?

- provincial ministry of health and wellness
- 60 hospice palliative care stakeholders across the province

Steps Taken:

1. A two-day meeting was held to talk about the critical issues in rural hospice palliative care and identify ways the government, the voluntary sector and other stakeholders could work collaboratively to meet the challenges.
2. An ad hoc working group was formed to define the structure and mandate for a provincial strategic alliance for hospice palliative care.
3. The group supported the core values and guiding principles in the Model, adapting some of the principles to reflect the provincial context.
4. The group developed a vision, mission and goals for the alliance that set out a unique provincial role that would complement existing hospice palliative care organizations.
5. The group established outcomes that the alliance would achieve, including using the Model to:
 - define hospice palliative care at the provincial level (e.g., criteria to receive services, eligible services, patient and family access to support)
 - identify strategies to reduce barriers to accessing hospice palliative care
 - develop provincial guidelines for hospice palliative care.

6. Using the square of organization, the group identified the resources required to support the alliance and the functions it will fulfill.

Impact/Lessons Learned:

The Model provided the language and definitions to build the structure.

The Model provided the group with exhaustive information and highlighted what can be expected from policy decision makers (e.g., access 24 hours-a-day, 7 days-a-week).

It also encouraged the group to think about the entire spectrum of hospice palliative care, including fundraising and advocacy.

Because of its robust methodology, the Model enhanced the credibility of the concept and structure.

Through the process of using the Model, the network of provincial champions was strengthened identifying common areas for collaboration and recognizing unique regional opportunities and challenges.

3. Using the Model to Guide Planning

The Model sets out principles and norms that hospice palliative care programs, services and organizations can use to guide their strategic planning and business/program planning (i.e., the resources and functions required to support their activities). The Model can also be used to plan projects, service delivery models, new services – any aspect of hospice palliative care.

3.1 Planning a legacy project

Volunteers in a hospice palliative care program wanted to develop a legacy quilting project for patients and families. Each patient/family would create a quilt square that captured the spirit of the dying person. The quilt would hang on a wall in the hospice, and grow over time: a legacy of the people who used the hospice.

Goals:

- To celebrate people’s lives.
- To provide support for patients and families.
- To facilitate the bereavement process.

Who’s Involved?

- Recreation therapist and staff members
- The volunteers managing the project
- Patients
- Families

Steps Taken:

1. The recreation therapist evaluated patients’ needs and ability to participate in the project.
2. Working with the recreation therapist and using the square of care, the volunteers identified the issues the project would address:
 - psychological – personality and strengths, dignity, self-image
 - social – cultural values, relationships, rituals;
 - spiritual – meaning, value, symbols.
3. They identified the steps in the process of providing care they would use to involve patients/families:
 - information sharing – to let patients/families know about the project and choose whether they wanted to participate;
 - decision-making – to work with patients/families to decide the best way for them to participate and identify any help they would need.

Components of the Model

Principles (page 30)

P2.1 It is a patient’s and family’s right to be informed about hospice palliative care and what it can offer throughout their illness and bereavement experience.

P2.2 It is the patient’s right to choose to be informed about his/her illness, available therapeutic options and their potential benefits.

Norms (page 31)

N3.5 The patient is offered therapeutic options to relieve suffering, and improve the quality of life that:

- are appropriate for the disease status and prognosis, goals for care, prioritized issues and the presumed etiologies of those issues
- have the potential for benefit
- are not associated with unacceptable risk or burden.

4. They used the square of organization to identify the resources required:
 - human – the project would be managed by the volunteers so it would not require staff time
 - physical – the project would require some space to store materials and that was identified
 - financial – families provided some of the materials, and the volunteers were able to get the rest donated by a local fabric store, so there were essentially no financial implications for the program.
5. They delivered the project, and the recreation therapist evaluated its outcome.

Impact/Lessons Learned

The Square of Care and Organization was critical in identifying the steps to take. It highlighted the importance of including volunteers in planning a hospice palliative care project and helped ensure the planning team addressed possible gaps.

In a volunteer led project, it is still essential to have a staff member (e.g., a recreation therapist or volunteer manager) involved to perform certain functions that require professional skills, such as evaluating patients’ psycho-social, emotional and spiritual needs as well as the outcome of the project.

Volunteers’ presence 24/7 is an important component for information sharing, decision making, providing resources, and delivering and evaluating the project.

3.2 Developing a service delivery model for rural and remote areas

A regional hospice palliative care program is responsible for providing hospice palliative care in a large area with many rural and remote communities. The program does not have enough staff with specialized skills in hospice palliative care to serve these communities, and it would not be cost effective to locate specialized hospice palliative care services in those locations.

Goal:

- To develop a service delivery model designed to give people in rural and remote communities equitable access to high quality hospice palliative care.

Who’s Involved?

- The regional hospice palliative care program
- Primary care providers in the communities
- The voluntary sector
- People in the communities

<p>Components of the Model</p> <p>Square of Care (page 27)</p> <p>Square of Organization (page 45)</p>

Steps Taken:

1. The regional hospice palliative care programs worked collaboratively with the communities to identify local caregivers and volunteers who could play a role in providing hospice palliative care.
2. The planning team identified the issues that local providers/volunteers could address – based on their skills and scopes of practice, and the issues that would require some specialist resources/supports.
3. The regional hospice palliative care program worked with the providers and volunteers to identify the education and support they needed to be able to provide high quality hospice palliative care, including:
 - training programs
 - incentives, telephone and computer links with the central hospice palliative care program
 - quick access to specialists
 - a mentorship program
 - a visiting specialist program
 - a referral system for patients who can no longer be cared for at home/in the community
 - transportation services for patients
 - access to relief and other services for family caregivers
 - accommodation for family members if patients have to be referred.
4. The regional hospice palliative care program identified the resources required to provide that service (i.e., financial, physical, informational), and advocated for those resources.
5. The program worked with local caregivers, volunteers and families to develop standards for service delivery based on the principles and norms.

Results/Lessons Learned

Using the Model helped planners identify the services required and then the providers who could deliver those services.

The Model helped reinforce the essential role of informal caregivers and volunteers in hospice palliative care in rural and remote communities

3.4 Planning a Rural Residential Hospice

Goal:

- To develop a rural residential hospice.

Who's Involved?

- A Volunteer Hospice Board -- members with experience in all areas of management, including legal, financial, medical and fundraising

Components of the Model

Values (page 19)

Guiding principles (page 19)

Square of Care (page 27)

Square of Organization (page 45)

- Community partners – including the local hospital, long-term care facilities, placement services, community agencies, local municipal government, volunteers

Steps Taken:

1. A small group of community leaders who were committed to hospice palliative care organized a series of public meetings to assess the community's support for a residential hospice.
2. A community needs assessment was conducted to document the need for a residential hospice.
3. The Volunteer Hospice Board was established by seeking out people in the community with the necessary knowledge, skills and commitment.
4. Members of the Board reviewed the CHPCA Principles and Norms of practice to guide their planning.
5. The Board developed links with key provincial hospice and palliative care groups and associations.
6. The Board developed a mission statement and values for the proposed hospice.
7. The Board incorporated, obtained board liability insurance and charitable status.
8. The Board worked with community partners to:
 - plan the model of care and the size of facility
 - develop the business plan
 - identify capital/operational costs
 - acquire land.
9. The Board developed formal service agreements with community partners to provide services to support the hospice.
10. The Board developed funding proposals to submit to the provincial ministry of health and investigated other possible sources of funding, including corporate donations and grants. The Board also developed formal fundraising plans.
11. The Board worked with community partners to develop policies and procedures for the hospice.
12. The Board developed a plan and materials for community education and ongoing public relations.

Impact/Lessons Learned:

People who are living with a life-threatening illness and their families want hospice palliative care close to home. Small communities can benefit from a residential hospice palliative care program

Using the CHPCA Model provided a framework for developing hospice palliative care services in a small rural community.

Using the CHPCA Model gave the planning process more credibility with the health care community.

The Model has to be adapted to meet rural needs.

Close collaboration with community partners is essential for good implementation of the Model, and to meet needs and maintain good community relations.

4. Using the Model to Strengthen Clinical Programs and Services

As the Model notes, hospice palliative care is highly interdisciplinary and is based on three foundational concepts: effective communication, effective group function and the ability to promote and manage change. These concepts include sharing a common language, using common protocols, collecting consistent and useful information, developing effective teams, managing challenges and adapting. They are fundamental to develop effective therapeutic relationships and providing high quality hospice palliative care. The following examples illustrate how hospice palliative care programs and services can use these foundational concepts as well as the Square of Care and other professional guidelines to improve and strengthen clinical services.

4.1 Developing and Evaluating a Clinical Tool

A hospice palliative care program used the Model to develop and test a chart in the home, which would be used by both formal and informal caregivers to track the patient's needs and the care/services provided in the community.

Goal:

- To develop a chart that both formal and informal caregivers could use to track the patient's care in the home
- To provide greater continuity of care for patients in the home

Who's Involved?

- Members of a regional hospice palliative planning group
- An interprofessional ad-hoc subcommittee

Steps Taken:

1. The work group reviewed and discussed the values, guiding principles, foundational concepts and norms, and came to a common understanding of the ones that would shape the chart and how it would be used.
2. The group developed a draft chart.

Components of the Model

Values (page 19)

V3. The need to address patients' and families' suffering, expectations, needs, hopes and fears.

V6. Caregivers enter into a therapeutic relationship with patients and families based on dignity and integrity.

V7. A unified response to suffering strengthens communities.

Guiding Principles (page 19)

GP2. High Quality

GP3. Safe and Effective

GP6. Collaborative

Foundational Concepts (page 21)

FC1 Effective Communication

FC1.2 Use a standard protocol to communicate, and to listen and respond

FC1.3 Collect data that documents the patient's and family's status, and provides a record of each therapeutic encounter

Assessment Principles and Norms (page 28)

P1.4: Evidence-based tools

N1.2: History-taking information

N1.4: Without undue burden

3. The group reviewed the chart against the Square of Care to ensure that it covered all domains of issues and all aspects of care. During this step, the group identified that spiritual issues had not been included in the draft and added them.
4. The group tested the chart with formal and informal caregivers to ensure that it was “friendly” and easy to use.
5. The group identified the resources required to implement the chart, including information and training for caregivers and family members.
6. Informal and formal caregivers began using the chart, and its use was evaluated.

Impact/Lessons Learned:

The process of creating the chart in the home was extremely valuable in building the long-lasting relationships required to work together as a community – particularly in a province that does not have regional service delivery models.

Developing the chart took a long time, lots of patience, and perseverance.

By reviewing the Square of Care, the program was able to go ahead with confidence that the chart covered all the necessary bases.

Even though not everyone was completely satisfied with the chart in the home, the program had to start using it to truly see what worked and what did not work.

The evaluation process was multi-dimensional and multi-professional.

4.2 Developing Clinical Guidelines

“Video-visits” have the potential to significantly increase patients’ and families’ access to hospice palliative care – particularly in rural and remote areas – and to help programs make more effective use of specialized hospice palliative care skills and providers. A working group used the Model -- as well as other nursing guidelines -- to develop draft clinical guidelines for “video-visits” by nurses providing palliative home care.

Goal:

- To describe the role of the nurse in conducting video-visits in palliative home care.
- To provide guidelines for practice, education, organization and policy for programs implementing video-visits.
- To ensure a new service delivery model contributes to high quality hospice palliative care.

Components of the Model

- Definitions (page 17)
- Principles (page 19)
- Square of Care (page 27)
- Norms of Practice for Assessment (page 28)
- Data Collection/Documentation Guidelines (page 38)

Who's Involved?

- Hospice palliative care clinical nurse specialists
- Home care managers
- Hospice palliative care nurses consultants
- Community care coordinator
- Researchers who piloted the delivery model

Steps Taken:

1. The working groups used a process suggested by the provincial registered nursing association to define the purpose and scope for the guidelines.
2. The working group adopted the following CHPCA principles to guide all aspects of video-visits in palliative home care:
 - patient/family focused
 - high quality
 - safe and effective
 - accessible
 - adequately resourced
 - collaborative
 - knowledge-based
 - advocacy-based
 - research-based
3. The working group used components of the CHPCA's *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*, the CHPCA nursing standards and the Canadian Nurses Association (CNA) *Role of the Nurse in Telepractice* to develop a framework for the guidelines and make recommendations about the role of the nurse in telepractice.

Framework for Conducting Nursing Video-visits in Palliative Home Care

CHPCA “Square of Care”

<p>Common Issues in Hospice Palliative Care:</p> <ul style="list-style-type: none"> ▪ Disease management ▪ Physical ▪ Psychosocial ▪ Social ▪ Spiritual ▪ Practical ▪ End of life/Death management ▪ Loss & grief 	<p>Process of Providing Hospice Palliative Care:</p> <ul style="list-style-type: none"> ▪ Assessment ▪ Information sharing ▪ Decision-making ▪ Care planning ▪ Care delivery ▪ Confirmation
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CHPCA Nursing Standards

<ul style="list-style-type: none"> ▪ Valuing ▪ Connecting ▪ Empowering 	<ul style="list-style-type: none"> ▪ Doing for ▪ Finding meaning ▪ Preserving integrity
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CNA Role of the Nurse in Telepractice

Nurse-patient relationships	Competencies	Locus of accountability	Security, confidentiality & Privacy	Informed consent & patient choice	Professional practice environments
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Key Elements

<ul style="list-style-type: none"> ▪ Pre-existing relationship 	<ul style="list-style-type: none"> ▪ Nurse ▪ Patient/ Family 	<ul style="list-style-type: none"> ▪ Nurse 	<ul style="list-style-type: none"> ▪ “Secure” visit ▪ Documentation ▪ Technology security 	<ul style="list-style-type: none"> ▪ Options: face-to-face or video-visit or telephone only ▪ Consent reflects patient choice 	<ul style="list-style-type: none"> ▪ Policies ▪ Protocols ▪ Outcomes
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Hebert MA, Paquin MJ, Janzen C, Nummi D, Whitten L, & Yamabe C. (2003). *Nursing guideline for “video-visits” in palliative home care – Working group’s final draft, May 26, 2003.* Calgary, AB: Health Telematics Unit, University of Calgary.

4. The CHPCA Model was used to help develop recommendations for defining who will be involved in the patient's care, establishing a therapeutic relationship, setting out the frequency and steps for each therapeutic encounter, conducting the initial assessment, and collecting data and documenting each therapeutic encounter.

Impact/Lessons Learned:

The CHPCA Model helped define a best practice framework for conducting video-visits.

It also provided guidance in developing recommendations for: nurse-patient relationships; competencies; locus of accountability; security, confidentiality and privacy; informed consent and patient choice; and professional practice environments.

The framework and recommendations developed via consensus are being validated through a three-year multi-method study. It will help build the evidence for hospice palliative care telenursing.

4.3 Developing Referral Criteria

According to the literature, patients at end of life have high prevalence of dietary problems. A dietitian in a hospice palliative care program was concerned that patients who could benefit from nutrition services were not being referred.

Goal:

- To ensure that all patients receive timely and appropriate referrals for nutrition assessments.
- To raise staff awareness about how dietary strategies can improve quality of life.

Who's Involved?

- Dietician
- Staff who do patient assessments

Steps Taken:

1. The dietitian identified the domains of issues that her services affect (i.e., physical, disease management, psychological, social, spiritual) and the steps during the process of providing care when patients should be referred for a nutrition assessment if required (i.e., assessment, care planning).
2. The dietitian audited all the patient charts to determine: which patients had been referred; which referrals were appropriate, which were not; and the patients who should have been referred but were not.
3. The dietitian developed criteria for referrals to dietary services based on the principles and norms.
4. Based on the referral criteria, the dietitian will identify ways to improve the assessment process and care planning to ensure people are referred appropriately (e.g., fine tuning some of the questions on the assessment form, ensuring dietary needs were listed in the forms for care planning).
5. The dietitian will also develop an education session for staff doing the assessments to provide more training on identifying dietary symptoms and issues (e.g., nausea, vomiting, dehydration, swallowing) and how dietary strategies can improve quality of life.
6. The dietitian will monitor future referrals, and continue to work with staff to ensure patients are referred appropriately.

Components of the Model

Square of Care (page 27)

V3. The need to address patients' and families' suffering, expectations, needs, hopes and fears. (page 19)

V5. Care is guided by quality of life as defined by the individual (page 19)

GP7. Knowledge Based (page 20)

GP9. Research-Based (page 20)

Impact/Lessons Learned

The dietitian needed guidance from someone with skills in evaluation or continuous quality improvement (CQI) to map out the process for assessing referral patterns.

The six essential elements for providing care (square of care) were useful in determining when and how nutritional referrals should take place.

4.4 Assessing Quality/Checking Current Practices Against the Norms

The Model can be used to assess the quality of a therapeutic encounter or a service. A hospice palliative care training program uses the Model to encourage participants to reflect on the quality of their practice.

Goal:

- To help hospice palliative care providers understand how to apply the principles and norms.
- To encourage hospice palliative care providers to continually assess their practice.

Who's Involved?

- The trainer
- Hospice palliative care providers

Steps Taken

1. The trainer introduced the Square of Care, reviewed the issues associated with illness and bereavement, and explained how to use the Square of Care to identify issues and provide quality care.
2. The trainer then asked providers to read the principles and norms, and circle the norms that reflect their current practice.
3. Participants were able to identify their strengths and weaknesses, and talk about ways they could change their practice to reflect the norms.

Impact/Lessons Learned

Participants felt the training session provided new knowledge and highlighted the areas of practice that needed improvement.

Similar sessions for managers/decision-makers would be helpful in identifying policy and procedures, standards of practice and clinical guidelines that need to be revised, updated or developed.

Components of the Model

Square of Care (page 27)

Principles and Norms of Practice (page 28)

4.5 Building Partnerships

A regional hospice palliative care program used the Model to build a closer relationship with other organizations in the community providing services for patients at the end of life.

Components of the Model

Square of Care (page 27)

Square of Organization (page 45)

Goal:

- To develop a closer working relationship with the cancer centres.
- To improve cancer patients' access to hospice palliative care.

Who's Involved?

- The regional hospice palliative care program
- Regional cancer centres

Steps Taken:

1. The regional hospice palliative care program used the CHPCA principles and norms to help define its role with other services in the community. Through that process, the program recognized that it had a responsibility to ensure that everyone in the region had access to high quality hospice palliative care.
2. The program worked to develop a closer relationship with the cancer centres, so patients would be referred more appropriately and hospice palliative care could become involved early enough to be able to “improve the quality of living and dying”.
3. The program made hospice palliative care nurses available to the cancer centres, so they could consult with them on cases.
4. The hospice palliative care nurses held an education session for the cancer providers, and explained:
 - the eight domains of issues that patients and families face at the end of life
 - how these issues present
 - how cancer staff can assess patients and families for any unmet needs
 - the services and approach that the hospice palliative care team takes to meet these needs.
5. The nurses also worked with the cancer centres, based on the norms, to develop criteria to ensure more appropriate, timely referrals to hospice palliative care.

Impact/Lessons Learned

The regional hospice palliative care program now reports that, whenever the cancer centres identify patients and families with issues in any of the eight domains, they routinely call the hospice palliative care team.

4.6 Evaluating/Accrediting a Hospice Palliative Care Program

The Canadian Council on Health Services Accreditation (CCHSA), which is responsible for accrediting hospice palliative care programs within hospitals and in other health care settings across Canada, is using the Model to develop accreditation standards for hospice palliative care.

Goal:

- To identify accreditation standards for hospice palliative care.

Who's Involved?

- A subcommittee of the Best Practices Work Group, under the Secretariat of Palliative and End of Life Care, Health Canada.
- The Canadian Council of Health Services Accreditation (CCHSA)

Components of the Model

Values (page 19)

Guiding Principles (page 19)

Foundational Concepts (page 21)

Principles (page 28)

Norms (page 28)

Steps Taken:

1. The CCHSA took the CHPCA values, guiding principles, foundational concepts, norms and principles, and integrated each element into their Achieving Improved Measurement (AIM) standards for the accreditation documents.
2. Ten hospice palliative care programs and services from across Canada were asked to pilot the accreditation documents in the spring of 2005.

Impact/Lessons Learned

The CCHSA found that the elements of the CHPCA Model were similar to their AIM standards, so they were able to merge the two models easily.

Hospice palliative care programs will be able to voluntarily use the Hospice Palliative Care accreditation standards to determine their strengths and areas for improvement.

5. Using the Model to Guide Education

Hospice palliative care is a relatively young specialty. When hospice palliative care programs, services and organizations adopt the Model, they make a commitment to continuously work to improve the quality and consistency of hospice palliative care. The quality and consistency of care depends to a great extent on the knowledge and skills of hospice palliative care providers (professionals and volunteers). Over time, the Model will lead to accreditation standards for hospice palliative care, core competencies, formal education programs, and licensure standards for providers.

On this journey, hospice palliative care programs, services and organizations can use the Model to identify the education and training that providers need, while developing orientation and continuing education programs that supports knowledge and skills development which is based on the Model elements.

When organizations use the Model to guide education, they are then able to assess the impact of the education on practice. For example, if a program identifies a problem with managing patients with terminal delirium, and provides education to address the problem, it should then be able to track the activity and determine whether the education had an impact. In these cases, the organization should set some measurable outcomes for the education.

5.1 Assessing Competencies and Developing Learning Plans

A hospice palliative care unit merged two models – the Canadian Nurses Association (CNA) Nursing Competencies and the CHPCA Model – to set out a new set of nursing competencies for nurses on the unit. The unit then used the new competencies to help them develop, implement and evaluate each nurse’s annual learning plan.

Goal:

- To identify the competencies for hospice palliative care nurses on the hospice palliative care unit.

Who’s Involved?

- Unit nurse manager
- Advanced practice nurse for hospice palliative care
- Hospice palliative care nurses
- Director of the hospice palliative care service

Steps Taken:

1. The team worked together to map the CHPCA competencies on the Square of Care and into the nursing competencies model.
2. They were then able to describe the competencies they needed in the unit to work to the norms.

Components of the Model

Square of Care (page 27)

Impact/Lessons Learned

The unit uses the competencies to help recruit nurses with the rights skills, to plan nurse orientation and other in-service training, to enable nurses to conduct annual self-evaluations for self-directed learning.

5.2 Developing Orientation and Education Programs and Identifying Education Priorities

Organizations can use the Model to develop orientation and ongoing education for staff and volunteers.

Goal:

- To ensure that staff and volunteers understand the principles and norms that guide hospice palliative care in Canada.

Who's Involved?

- Trainers
- Managers

Steps Taken:

1. When introducing new staff and volunteers to a hospice palliative care program, managers/trainers include in orientation sessions:
 - the definitions, values, guiding principles and foundational concepts that guide hospice palliative care in Canada
 - the square of care and organization and how it is used
 - the principles and norms, and their relevance for different patients and families
 - the organization's expectations of how staff and volunteers will use the norms
 - the policies, procedures and standards the organization has adopted to operationalize the norms.
2. When developing ongoing education programs, organizations use the Model to identify areas where programs do not reflect the norms and provide education to help move staff and volunteers closer to the norms of practice.
3. When organizations face competing demands for education resources, they use the Model to identify where the needs are most urgent needs (e.g., largest gaps between practice and norms) and use that information to set priorities. In some cases, this might mean investing in education that targets other services in the community (e.g., home care providers, family physicians) before some in-service education.

Components of the Model

Definitions (page 91)

Values (page 19)

Guiding Principles (page 19)

Foundational Concepts (page 21)

Square of Care (page 27)

Square of Organization (page 45)

Principles and Norms (page 28)

Impact/Lessons Learned

The way education is provided and the materials used should reflect the principles of adult education.

5.3 Developing Best Practices for Volunteer Services

The Volunteer Best Practices Taskgroup, a subcommittee of the national Best Practices Work Group under the Secretariat of Palliative and End of Life Care, Health Canada, is using the Model to develop best practices for volunteer services.

Goal:

- To develop a companion document to the CHPCA Model that illustrates best practices, competencies and educational components for volunteer services based on the norms.

Who's Involved?

- Volunteer Best Practices Taskgroup: eight palliative care volunteer coordinators from across Canada
- Senior policy analyst from the Secretariat
- An extended taskgroup made up of 60 volunteer coordinators and volunteers from across Canada who will review and edit the draft documents.

Components of the Model

Values (page 19)

Principles (page 19)

Foundational Concepts (page 21)

Square of Care (page 27)

Square of Organization (page 45)

Steps Taken:

1. Using the program's expertise and evidence (existing program materials and literature), the Taskgroup reviewed the Model for Volunteer Services including:
 - adapting the Values, Principles, Foundational Concepts (pp 9-13)
 - adapting the square of care (pp 56-63)
 - adapting the square of organization (pp 46-52)
 - developing appropriate policies, procedures and standards (pp 83-85)
2. The Taskgroup sent the information to all palliative care programs across Canada for their input.
3. After incorporating the input, the Taskgroup hosted a national consensus forum in 2004. Sixty volunteer coordinators and volunteers from across Canada were invited to further edit and draft Volunteer Competencies and core educational needs.
4. The Taskgroup is currently finalizing the materials and drafting the educational components.

Impact/Lessons Learned

The work of the Taskgroup actually sets the stage for the CCHSA hospice palliative care standards described in Section 4.6.

Volunteers will have a common reference for understanding their roles and their program's responsibilities towards the volunteers.

5.4 Developing Education Activities for Courses, Workshops and in-service Training

Hospice palliative care programs, services and organizations can develop learning education activities for orienting and training staff and volunteers that are based on the Model and help reinforce the Model.

Goal:

- To use interactive and applied learning activities to teach/reinforce the CHPCA Model.

Steps Taken:

1. Create a page with the headings of each domain (see page 15 of the Model).
2. Ask learners to develop the list of items that could fall within each domain.
3. Ask learners to compare their efforts to the model on page 15.
4. The same exercise can be done with the six essential steps, the guiding principles, the norms and values.

Components of the Model

Domains of Issues Associated with Illness and Bereavement (Figure #7, page 15)

Guiding Principles (page 19)

Essential and Basic Steps During a Therapeutic Encounter (Figure #10, page 26)

Lessons Learned:

This is an effective method that applies the principles of adult education to the learning activity. The activity is interactive, practical and relevant.

5.5 Planning a Conference

A conference can be organized around a specific step in the process of providing care, such as information-sharing – which often poses the greatest ethical challenges for caregivers.

Goals:

- To encourage greater consistency in a program's approach to information sharing.
- To give staff an opportunity to discuss the norms and ethical issues related to information sharing.
- To help staff develop information sharing techniques that support the norms of practice.

Components of the Model

Principles of Information Sharing (page 30)

Norms of Information Sharing (page 30)

Who's Involved?

- Hospice palliative care staff
- Family members of former patients
- A bioethicist
- A trainer

Steps Taken

1. Participants were divided into small groups including a mix of staff and family members to discuss the principles and norms and whether they agreed with them.
2. Organizers role played three information-sharing scenarios: one demonstrating best practices, the others illustrating some of the problems that arise when best practices are not followed.
3. In their small groups, participants discussed the scenarios, and what the staff did “right” and “wrong” in each situation, and how they could have been handled differently.
4. The ethicist gave a presentation on the ethical issues that caregivers may face in difficult situations, such as when family members ask a staff person not to reveal information to a patient or when the dying person is a child.
5. The trainer gave a presentation on different information sharing techniques.
6. In small groups, staff discussed personal experiences with information sharing that have challenged their ability to apply the norms of practice and how they could use the norms, techniques and other information from the conference to handle those situations differently. Family members reacted and gave feedback.
7. In a plenary session, participants identified the standards the program should have to achieve the norms for information sharing.

Impact/Lessons Learned

The principles and norms related to information sharing guided the small group discussions.

Using the principles and norms for information sharing helped participants realize that the concept of information sharing is broader than communicating the plan of care.

Using the principles and norms helped reinforce the importance of a patient/family-centered approach.

6. Using the Model to Manage a Hospice Palliative Care Program, Service or Organization

Most of the examples in this toolkit focus on providing care and services, but the CHPCA Model can also be used to help manage hospice palliative care programs, services and organizations and ensure they have the right mix of resources – people, money, information, space and supplies/equipment, and community support – to provide high quality, effective care. Hospice palliative care programs, services and organizations can also use the Model to identify and advocate for supportive hospice palliative care policies and funding, and to guide research. For example:

- **Advocating for Hospice Palliative Care Services.** The Model is a useful tool for advocacy as it is a comprehensive overview of the many facets that are involved in providing hospice palliative care. As highlighted in the Model, hospice palliative care is multidisciplinary in nature and whether developing laws, policies, or regulations it is important that all aspects of hospice palliative care are incorporated. With its conceptual frameworks, the “Square of Care” and the “Square of Organization” - the Model demonstrates the complex and multidisciplinary environment in which hospice palliative care is provided. It will assist those who are in a position to effect change to better understand what hospice palliative care is and will frame what consumers expect when receiving healthcare.
- **Recruiting and Hiring Staff.** Hospice palliative care programs that have made a commitment to work toward the principles and norms will want to recruit people who either already share the same commitment to patient/family-focused care, or who have the right “attitude” and skills to be part of a hospice palliative care team. They can use the Model to help write job descriptions and to develop interview questions that reflect the Model (e.g., what does patient-centered care mean to you?).
- **Budget Planning.** As part of budgeting exercises, hospice palliative care programs, services and organizations can use the Model to justify budget requests. Any request for new funding for a project or activity would demonstrate how the proposed activity will enhance the program’s capacity to achieve the norms as presented in the Model. They can also take a norms-based approach to allocating new resources or implementing funding cuts.
- **Promoting Hospice Palliative Care.** Any promotional materials developed by hospice palliative care programs or any media information should include or reflect the Model.
- **Setting Research Priorities.** Research in hospice palliative care can benefit greatly from using the Model as a basis for pursuing research opportunities. Hospice palliative care research has been identified through the NET (New Emerging Teams)

grants through the Canadian Institutes of Health Research's (CIHR) Institute of Aging and Institute of Health Services and Policy Research as a key area that is important to explore. Organizations and institutes with an interest in research regarding palliative care can use the Model as a basis for framing research ideas and conducting leading-edge research. An example of research is a project, being conducted through the University of Ottawa with CIHR's Institute of Aging, Institute of Cancer Research, Institute of Health Services and Policy Research on optimizing end-of-life care for seniors. These research initiatives can use the Model as a basis to develop leading-edge research in hospice palliative care.

7. Summary

The publication of *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* in 2002 was a pivotal point in the development and ongoing commitment to the provision of quality hospice palliative and end-of-life care services in Canada. The Model has established a baseline for core components of a hospice palliative care program or service and the goalposts that all hospice palliative care services and programs in Canada should be striving to reach. As mentioned in the Background section of this Toolkit, organizations are **not** expected to implement the complete Model across their hospice palliative care programs, services and organizations **all at once**. Programs and services should start where they are and, over time, use the Model to shape and strengthen all aspects of their practice. It is critical that this toolkit be used in conjunction with *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* as specific pages in the Model are referenced throughout this toolkit.

This toolkit provides specific examples of how the Model has been used to guide aspects of planning and delivering hospice palliative care services. Aspects covered by this Toolkit include:

- Policy Development
- Program or Service Planning
- Strengthening Clinical Program and Services
- Education
- Managing a Hospice Palliative Care Program, Service or Organization including:
 - Advocacy
 - Human Resources
 - Budget Planning
 - Promotion
 - Research

Organizations that have used the Model describe it as a catalyst for reviewing and improving practice, or as a touchstone that they continually use to ensure they are achieving their goals and making progress in fulfilling their mission. They stress that the Model is not a recipe - it does not tell hospice palliative care programs and services what to do or how to do it. What the Model does do is describe the desired practice all programs and services should be trying to achieve. Each organization must determine for themselves the best way to reach this goal.