

# **A Model to Guide Hospice Palliative Care:**

**Based on National  
Principles and Norms of Practice**



**Canadian Hospice Palliative Care Association**

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**Association canadienne de soins palliatifs**

**March 2002**

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# **A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice**

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# Preface

Since the discovery of penicillin in the 1940s, the experience of illness has been changing. Modern medicine has been very successful fighting disease, other conditions, and aging. In the 21<sup>st</sup> century, people are living with illness for much longer than ever before. Today, they must deal with many complex issues: How can they get relief from their symptoms? How can they carry on with life as they have known it? How will the illness affect their roles and relationships? What can be done to change the illness experience? How can they restore or maintain their capacity for meaningful and valuable experiences that give quality to their lives? <sup>1</sup>

Each of these issues creates expectations, needs, hopes and fears, which must be addressed in order for the ill person to adapt, continue living, and find opportunities for growth. For many years, the approach used in hospice palliative care has helped patients and their families address these issues while they were dying. Now, all the skills and strengths developed in hospice palliative care can be applied throughout the experience of illness and bereavement to help patients and families improve the quality of their lives, increase their ability to participate in therapy to fight their disease and, potentially, prolong their lives.

The practice of hospice palliative care is relatively young. In Canada, it began in the 1970s and has evolved rapidly. The term “hospice palliative care” was coined to recognize the convergence of hospice and palliative care into one movement that has the same principles and norms of practice.

In a consensus-building process led by the Standards Committee of the Canadian Hospice Palliative Care Association, providers, organizations and consumers joined to share their experiences and develop a clear vision for hospice palliative care that everyone could use. The resulting model represents more than 10 years of collaboration by individuals, committees, associations and governments across Canada and is based on the nationally accepted principles and norms of practice. This document includes the:

- rationale for a national model, and the process used to develop it
- definition, values, guiding principles and foundational concepts that form the basis for hospice palliative care
- frameworks, principles and norms of practice to guide patient/family care, and organizational development and function
- application of the model to other activities, such as education, quality management, research, policy and funding, and consumer advocacy and marketing.

Everyone is encouraged to use the model to guide all activities related to hospice palliative care, and develop local standards of practice. Ultimately, it is hoped that instead of being seen as “care for the dying,” hospice palliative care will be known as “care that aims to relieve suffering and improve quality of life throughout the illness and bereavement experience, so that patients and families can realize their full potential to live even when they are dying”.

# OVERVIEW OF THE MODEL TO GUIDE HOSPICE PALLIATIVE CARE

## BACKGROUND

Changing Illness and Bereavement Experiences

Multiple Domains of Issues Cause Suffering and ↓ Quality of Life

1. Disease Management
2. Physical
3. Psychological
4. Social
5. Spiritual
6. Practical
7. End-of-life Care/ Death Management
8. Loss, Grief

## DEFINITION OF HOSPICE PALLIATIVE CARE

- Values
- Principles
- Effective Communication
- Effective Group Function
- Change Strategies

### GUIDE TO PATIENT & FAMILY CARE

- Square of Care
- Principles & Norms of Practice
- Preferred Practice Guidelines
- Data Collection/ Documentation Guidelines

### GUIDE TO ORGANIZATIONAL DEVELOPMENT & FUNCTION

- Mission & Vision
- Square of Organization
- Principles & Norms of Practice

## APPLICATIONS

- Clinicians/ administrators
- Quality managers
- Policy makers
- Researchers (clinical)
- Advocates (consumer)

- Administrators/ clinicians building organizations
- Careteam leaders
- Quality managers
- Policy makers
- Researchers (systems)
- Advocates (systems)

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# Table of Contents

<b>Acknowledgements</b> .....	<b>i</b>
Production of the Guide .....	i
Assistance with Internet Data Collection .....	i
CHPCA Standards Committee .....	i
Advisors.....	ii
Others Who Assisted with the Consensus-building Process.....	ii
Guide Reviewers.....	iii
Provincial Champions.....	iii
<b>Preface</b> .....	<b>v</b>
<b>Table of Contents</b> .....	<b>vii</b>
<b>Table of Figures</b> .....	<b>x</b>
<b>Background</b> .....	<b>1</b>
<b>Why a Standardized Approach to Hospice Palliative Care?</b> .....	<b>1</b>
<b>Why a National Model for Hospice Palliative Care?</b> .....	<b>2</b>
<b>The Process of Developing a National Consensus-based Model</b> .....	<b>4</b>
Phase 1 – Committee Consensus (1993-1995) .....	4
Phase 2 – National Consensus (1995-2000) .....	5
Phase 3 – National Consensus (2000-2001) .....	5
<b>Why Norms Instead of Standards of Practice?</b> .....	<b>6</b>
Projected Improvement in Practice .....	7
<b>References</b> .....	<b>8</b>
<b>The Model to Guide Hospice Palliative Care</b> .....	<b>11</b>
<b>I. The Understanding of Health and Illness Underlying the Model</b> .....	<b>12</b>
The Illness Experience.....	12
Who is Affected by the Illness.....	13
Multiple Complex Issues .....	14
Associated Expectations .....	14
The Health Care System's Response .....	14
<b>References Part I</b> .....	<b>16</b>
<b>II. Hospice Palliative Care: Definition, Values, Principles and Foundational Concepts</b> .....	<b>17</b>
<b>Definition of Hospice Palliative Care</b> .....	<b>17</b>
<b>The Role of Hospice Palliative Care During Illness</b> .....	<b>18</b>
<b>Values</b> .....	<b>19</b>
<b>Guiding Principles</b> .....	<b>19</b>
<b>Foundational Concepts</b> .....	<b>21</b>
FC1. Effective Communication .....	21
FC2. Effective Group Function .....	22
FC3. Ability to Facilitate Change.....	23
<b>References Part II</b> .....	<b>24</b>
<b>III. The Model to Guide Patient and Family Care</b> .....	<b>25</b>
<b>The Process of Providing Hospice Palliative Care</b> .....	<b>25</b>
<b>The Square of Care: A Conceptual Framework</b> .....	<b>27</b>
Elaboration of the Square of Care.....	27
<b>Principles and Norms of Practice</b> .....	<b>28</b>
1. Assessment .....	28

2. Information-sharing.....	30
3. Decision-making .....	31
4. Care Planning .....	33
5. Care Delivery .....	34
6. Confirmation .....	37
<b>Preferred Practice Guidelines.....</b>	<b>38</b>
<b>Data Collection/Documentation Guidelines .....</b>	<b>38</b>
Principles Guiding Data Collection.....	38
<b>References Part III .....</b>	<b>39</b>
<b>IV. The Model to Guide Organization Development and Function .....</b>	<b>41</b>
<b>The Nature of Hospice Palliative Care Organizations.....</b>	<b>41</b>
<b>Mission and Vision Statements .....</b>	<b>42</b>
Sample Mission Statement.....	42
Sample Vision Statement .....	42
<b>Resources .....</b>	<b>43</b>
<b>Principle and Basic Functions .....</b>	<b>44</b>
<b>Square of Organization: A Conceptual Framework .....</b>	<b>45</b>
<b>Principles and Norms of Practice.....</b>	<b>46</b>
7. Governance and Administration .....	46
8. Planning .....	47
9. Operations.....	48
10. Quality Management (Evaluation) .....	51
11. Communications/Marketing .....	52
<b>V. Application of the Model .....</b>	<b>53</b>
<b>The Integrated Square of Care and Organization.....</b>	<b>54</b>
<b>1. Applying the Model to Clinical Care .....</b>	<b>56</b>
Providing Hospice Palliative Care.....	56
The Development of a Therapeutic Relationship .....	57
Phases of a Therapeutic Relationship.....	58
Assessment.....	58
Information-sharing .....	59
Decision-making.....	59
Care Planning.....	60
Care Delivery .....	60
Confirmation.....	61
Development of Principles and Standards of Practice.....	62
Development of Policies and Procedures, Standards for Data Collection/Documentation ...	62
Other Clinical Applications .....	63
<b>2. Applying the Model to Organizational Development and Function.....</b>	<b>64</b>
Initial Idea .....	64
Phase 1: Prepare to Plan.....	66
Phase 2: Plan the Organization .....	66
Strategic Planning.....	66
<i>Define the Organization.....</i>	<i>66</i>
<i>Define Its Principle Activities.....</i>	<i>67</i>
<i>Define Its Clinical Services.....</i>	<i>67</i>
Potential Types of Care.....	67
Potential Service Delivery Models.....	68
Settings of Care.....	68
<i>Developmental Strategy.....</i>	<i>68</i>
Business Planning.....	69
Sell the Proposal.....	69
Phase 3: Implement and Run the Organization.....	70

Phase 4: Review the Organization Annually and Revise the Plan.....	72
Organizational Labelling.....	72
<b>3. Applying the Model to Careteam and Regional Team Development and Function .....</b>	<b>73</b>
Careteam Development and Function.....	73
Phase 1: Prepare to Plan.....	74
Phase 2: Plan.....	74
Phase 3: Implementation of the Plan.....	75
Phase 4: Review and Revise the Plan (Quality Management) .....	76
Phase 5: Adjourn.....	76
<b>4. Applying the Model to Quality Management.....</b>	<b>77</b>
Standards of Practice , Policies and Procedures, Standards for Data	
Collection/Development.....	77
Outcome Assessment .....	77
Performance Improvement .....	78
Accreditation .....	80
Standards of Professional Conduct.....	80
<b>5. Applying the Model to Education.....</b>	<b>81</b>
Medical Schools in Canada and the U.S. ....	81
Residency and Training Programs in the U.S.....	82
Continuing Medical Education Programs.....	82
<b>6. Applying the Model to Policy Development .....</b>	<b>83</b>
Population Data Surveillance Strategies .....	83
New Policy, Regulation, Law, Funding or Service Delivery Models .....	84
Minimum /Licensure Standards of Practice.....	84
<b>7. Applying the Model to Search .....</b>	<b>85</b>
<b>8. Applying the Model to Advocacy and Communications/Marketing .....</b>	<b>86</b>
Advocacy .....	86
Communications/Marketing.....	86
<b>Conclusion .....</b>	<b>86</b>
<b>References Part V.....</b>	<b>88</b>
<b>Appendicies.....</b>	<b>91</b>
<b>Lexicon of Commonly Used Terms .....</b>	<b>91</b>
<b>Additional Resources.....</b>	<b>97</b>
<b>Square of Care.....</b>	<b>99</b>
<b>Square of Care and Organization .....</b>	<b>100</b>
<b>Square of Organization .....</b>	<b>102</b>
<b>Further Information .....</b>	<b>103</b>
Reproduction.....	103
Attribution/Citation Statement.....	103
Information/ Additional Copies .....	103

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## Table of Figures

1: Application of a Model to Guide Hospice Palliative Care .....	3
2: Normative vs. Minimum Standard of Practice .....	6
3: Projected Improvement in Practice .....	7
4: Divergence from the Path of Life.....	13
5: Patient and Family .....	13
6: Changing the Experience of Illness .....	14
7: Domains of Issues Associated with Illness and Bereavement .....	15
8: The Role of Hospice Palliative Care During Illness .....	18
9: Groups in Hospice Palliative Care .....	23
10: Essential and Basic Steps During a Therapeutic Encounter.....	26
11: The Square of Care.....	27
12: The Principal Activities of Hospice Palliative Care .....	41
13: Resources to Support Hospice Palliative Care.....	43
14: Hospice Palliative Care Principal and Basic Functions .....	44
15: The Square of Organization.....	45
16: Interrelationship of the Square of Care and the Square of Organization.....	54
17: The Square of Care and Organization.....	55
18: Provider Roles in Hospice Palliative Care.....	56
19: Successive Encounters During the Development of a Therapeutic Relationship .....	57
20: Variation in Assessment by Phase of Relationship .....	58
21: Variation in Information-sharing by Phase of Relationship .....	59
22: Variation in Decision-making by Phase of Relationship .....	59
23: Variation in Care Planning by Phase of Relationship.....	60
24: Variation in Care Delivery by Phase of Relationship .....	60
25: Variation in Confirmation by Phase of Relationship .....	61
26: Development of Principles and Standards of Practice.....	62
27: Development of Policies and Procedures, Standards for Data Collection/Documentation .....	62
28: Planning Process for a Hospice Palliative Care Organization.....	65
29: Sample Table of Standards of Practice, Policies and Procedures, Standards for Data Collection and Documentation for a Specific Issue .....	71
30: Patient/Family Careteam .....	73
31: The Life Cycle of a Careteam .....	76
32: Comparison of Data from Successive Therapeutic Encounters.....	78
33: Quality Review Cycles .....	79
34: Review Frequency for Different Strategies.....	79
35: Minimum Standards of Practice .....	84

# Background

This section describes the rationale for a standardized approach to hospice palliative care, for a national model, and for the use of “norms” rather than “standards” of practice. It also describes the consensus process used to develop the model over the last 10 years.

---

## Why a Standardized Approach to Hospice Palliative Care?

Canada’s first hospice palliative care programs developed in the 1970s to respond to the needs of the dying. These programs were largely individual grass roots initiatives that have gradually evolved into a cohesive movement that aims to relieve suffering and improve quality of life for those who are living with or dying from an illness. Yet there continues to be considerable variability in the quality and availability of hospice palliative care. Although there are more than 600 programs across the country that deliver hospice palliative care, only a small proportion of Canadians living with a life-threatening illness have access to these programs. Many of the existing programs are not comprehensive, and are unable to address all of the issues faced by patients and families.

To ensure that all Canadians have access to consistent, high quality care that can relieve suffering and improve quality of life, Canada needs a more standardized approach to hospice palliative care. With this kind of approach, individual caregivers and organizations will be more consistent and effective at identifying patient and family issues, the care required to manage each issue, and the resources and functions needed to develop and manage hospice palliative care organizations.<sup>2</sup>

A standardized approach to hospice palliative care will help to:

- ensure all caregivers and staff are knowledgeable and skilled, and have the support they need to fulfill their roles
- reveal any gaps in care and encourage organizations to expand their services or develop partnerships with other healthcare providers to fill these gaps
- ensure each healthcare organization manages its activities, resources and functions in a manner consistent with its approach to care delivery.

While standardization encourages consistency, it doesn’t imply uniformity. Organizations will continue to differ in the ways they develop and function, and in the policies, procedures, and data collection/documentation strategies they develop to guide their provision of hospice palliative care.

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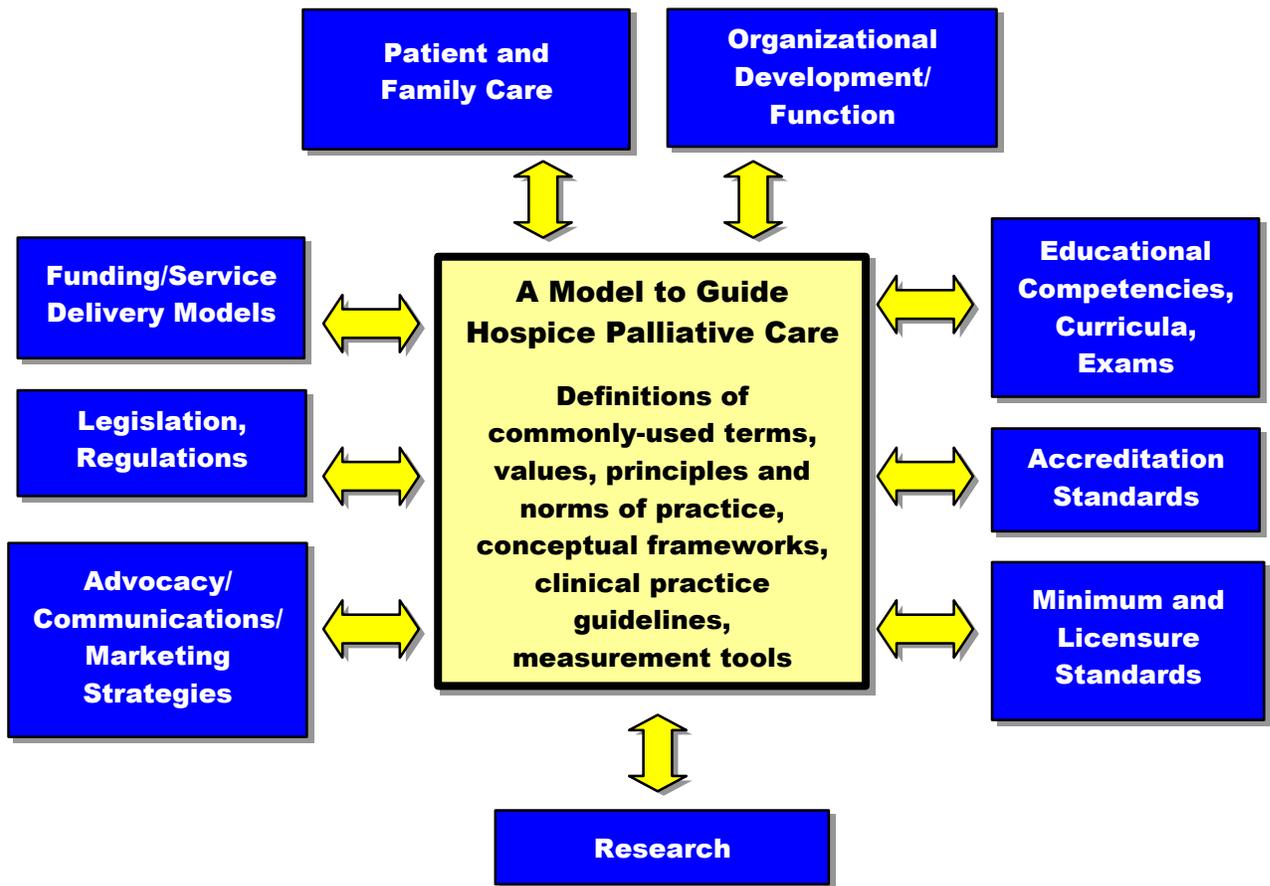
## Why a National Model for Hospice Palliative Care?

A national model for hospice palliative care is a tool to guide all activities related to it. When developed in consultation with experts across the country, and based on patient and family issues/needs (as opposed to existing funding and service delivery models), it creates a shared vision and sets the stage for a consistent, standardized approach to patient and family care, organizational development, education and advocacy across the country.

The consensus-based model developed by the Canadian Hospice Palliative Care Association (CHPCA) presents a lexicon of commonly-used terms, the values on which hospice palliative care is based, the principles and norms of practice, and the conceptual frameworks to guide each of the activities related to it. The model can be used to ([see figure #1 on the next page](#)):

- guide patient and family care provided by both primary and expert caregivers
- guide the development and function of hospice palliative care organizations
- develop core competencies, comprehensive curricula and examinations
- develop accreditation and minimum/licensure standards
- allow organizations to compare (benchmark) their practices to nationally accepted norms of practice, as well as against other hospice palliative care organizations
- guide research in hospice palliative care
- ensure consistency in advocacy, communication and marketing strategies
- promote laws, regulations and policies that facilitate rather than obstruct the provision of hospice palliative care
- develop funding and service delivery strategies that will ensure access to hospice palliative care when needed.

**Figure #1: Application of a Model to Guide Hospice Palliative Care**



Within the broader health system, a national model for hospice palliative care will:

- increase the credibility and facilitate maturation of this relatively young specialty
- help integrate hospice palliative care into mainstream healthcare
- serve as a model for the development of similar strategies to change other aspects of mainstream healthcare.

---

# The Process of Developing a National Consensus-based Model

Canada's hospice palliative care community has been working for a number of years to develop a more consistent approach to care. In 1981, Health and Welfare Canada published *Palliative Care Service Guidelines* (revised in 1989). In 1989, both the British Columbia Hospice/Palliative Care Association and the Metropolitan Toronto Palliative Care Council (MTPCC) started processes to develop more specific standards of practice. In 1991, the Ontario Palliative Care Association joined the MTPCC process. In 1993, the CHPCA consolidated all of these efforts into one national initiative to develop "norms of practice" that would:

- describe patient/family-centred hospice palliative care
- support the growth of current programs and guide developing programs
- provide a framework to evaluate the outcomes of hospice palliative care
- provide a foundation on which to build strategies to change national, provincial and regional healthcare policies, funding and service delivery systems.

In 1995, the CHPCA process received significant support from the Canadian Special Senate Committee on Euthanasia and Assisted Suicide report, *Of Life and Death*, which recommended that the development and implementation of national hospice palliative care guidelines continue.<sup>3</sup>

To develop accepted norms of practice that form the basis for a national model, the CHPCA Standards Committee led a nine-year consensus-building process that involved hundreds of participants. The three-phase process, which will be of interest to others trying to build a national consensus on principles and norms of practice, consisted of the following steps:

## Phase 1 – Committee Consensus (1993-1995)

The CHPCA Standards Committee:

- reviewed and collated existing standards and available literature<sup>4</sup>
- worked towards, and achieved, a committee consensus
- published *Palliative Care: Towards a Consensus in Standardized Principles of Practice 1995*.<sup>5</sup>

The consensus process was based on principles of group structure/ function:<sup>1</sup>

**Forming:** using provincial association representatives and champions to engage stakeholders to participate

**Storming:** acknowledging everyone will have different starting points and will need to express her/his opinion

**Norming:** providing structure and education to guide the process

**Performing:** using a sequential Delphi process<sup>2</sup> to reach consensus.

<sup>1</sup> Tuckman B. *Developmental Sequence in Small Groups*. *Psychological Bulletin*, 1965; 63: 384-399.

<sup>2</sup> Delphi Technique. In: *Nursing research*. Polit DF, Hungler BP (eds). JB Lippincott, 1991, 356-7.

## Phase 2 – National Consensus (1995-2000)

The CHPCA Standards Committee:

- distributed more than 5,000 copies of *Palliative Care: Towards a Consensus in Standardized Principles of Practice* to hospice palliative care providers/organizations across Canada
- established a Revisions Workgroup to conduct a consultation/consensus-building process
- established criteria to define consensus (i.e., consensus was achieved when: 75% of the respondents agreed with the concept/wording of a given item; < 10% of the respondents had not responded to the given item; and there were not a lot of consistent comments to the contrary)
- asked each of the 11 provincial hospice palliative care associations to recruit participants and host one or more workshops (17 workshops were held between June 1997 and February 1998)
- analyzed the quantitative and qualitative data from the 706 participants
- determined that consensus had been reached on 70% of the items in the English version, but that the French version needed further review
- summarized the progress to date in *How Close are We to Consensus 1998*<sup>6</sup> (completing the Phase 2 consultation on the English version)
- asked l'Association québécoise de soins palliatifs to facilitate further review of the French version
- received *Le Rapport Final*<sup>7</sup> from the Comité des normes de pratique de l'Association québécoise de soins palliatifs in 2000 (completing the consultation on the French version).

## Phase 3 – National Consensus (2000-2001)

The CHPCA Standards Committee:

- integrated the outcomes from the English and French consultations, and created a single document based on both sets of norms of practice (the results of each consultation influenced the other)
- revised the 1995 principles document and published the *2001 Proposed Norms of Practice*<sup>8</sup>
- developed an online questionnaire and a data collection tool which were posted on the CHPCA web site to gather feedback on the proposed norms of practice
- developed a team of champions to help disseminate the proposed norms, engage the hospice palliative care community in discussing them, and collect the feedback data
- analyzed the quantitative and qualitative data from 419 respondents
- determined that consensus had been reached on all of the items
- synthesized the experience and the feedback, and evolved the national model for hospice palliative care presented in this guide<sup>9</sup>
- had the model and this guide approved by the CHPCA Board of Directors (which includes the 11 provincial hospice palliative care associations in Canada).

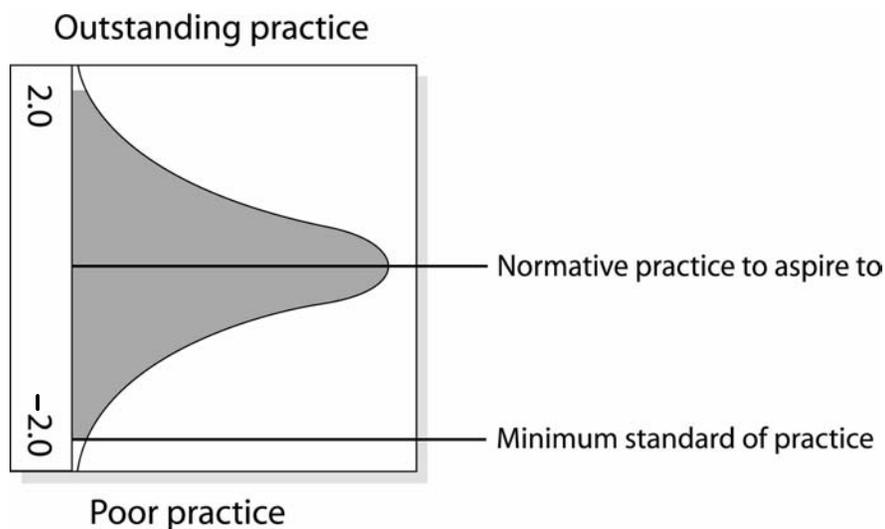
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## Why Norms Instead of Standards of Practice?

At the core of the model are “norms of practice.” Norms are simple statements that present the “usual” or “average” practice for hospice palliative caregivers and organizations. Norms are less specific or rigid than standards (which are defined as measurable conditions or states used as a basis for assessing quality and quantity).

As the following diagram illustrates, norms of practice are different from minimum standards (which typically describe the “floor” or minimum level of care that is acceptable, e.g., the US Medicare Hospice Benefit Conditions of Participation<sup>10</sup>). Norms set a higher level to which organizations can and should aspire.

**Figure #2: Normative vs. Minimum Standard of Practice**



While norms are different from standards, organizations can use the norms to establish their own standards of practice, and to guide patient, family and public expectations. For example, the norm for response times is:

“Requests for initial evaluation and ongoing follow-up are responded to within acceptable time frames.”

Based on that norm, an organization will develop a more specific standard of practice that will establish the minimum requirements to be met at all times:

“Requests for initial evaluation are responded to within 48 hours.”

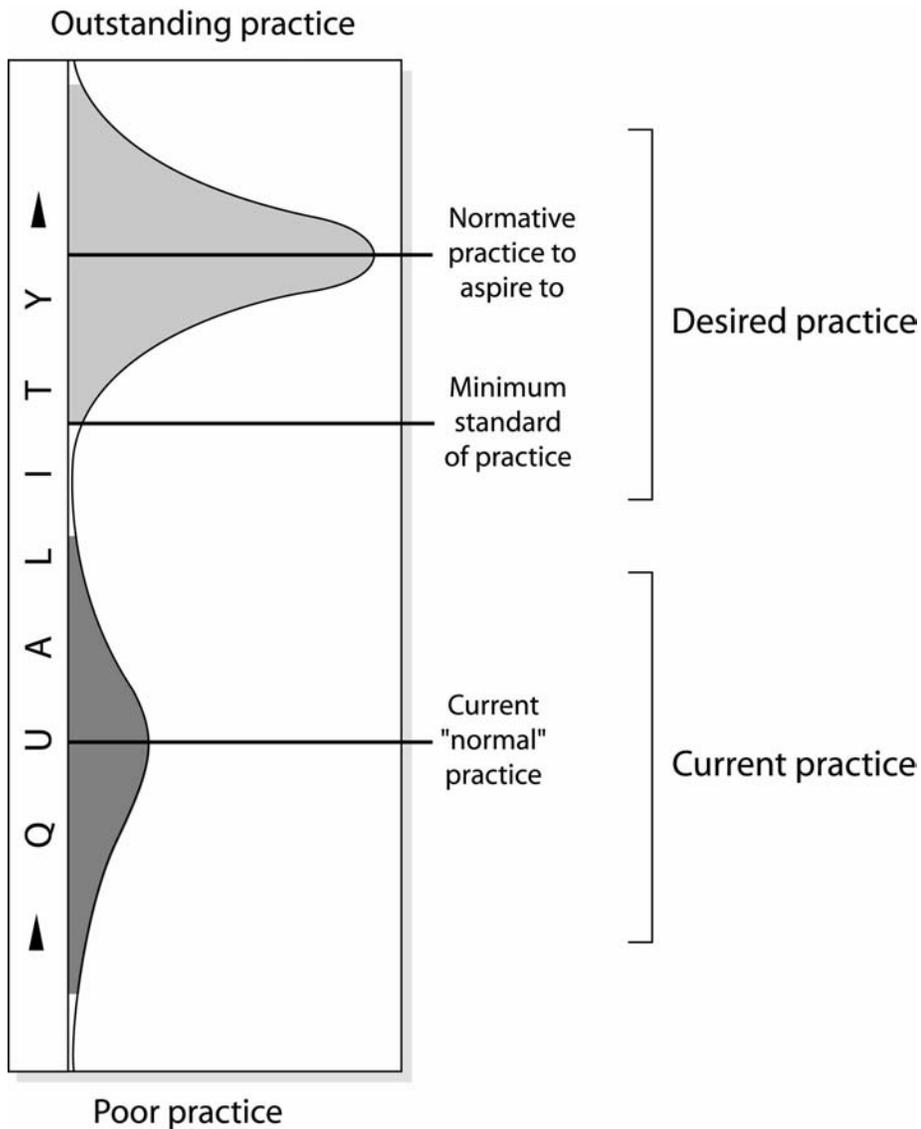
“Requests for ongoing follow-up are responded to within 12 hours.”

The model provides one or more norms of practice for each step in the process of providing care, and each aspect of an organization’s function. The norms in this first iteration of the model are not as specific as some might expect. This is because, in the early stages of a consensus process, it is neither possible nor desirable to be specific. As organizations use the norms, they will test them and gather evidence that can be used to refine the norms to be more specific and reflect actual and desired levels of practice.

## Projected Improvement in Practice

When organizations first start to use the model, there will most likely be considerable variability in current "normal" practice. With time it is anticipated that "normal" practice will improve and variability will diminish as organizations gain experience with the model. While most hospice palliative care organizations will aspire to the suggested norms of practice, there will always be organizations that vary from "normal" practice.

**Figure #3: Projected Improvement in Practice**



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**URLs were last updated March 23, 2002.**

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<sup>2</sup> Shine KI. *Health Care Quality and How To Achieve It*. New York, NY: Milbank Memorial Fund, 2002.

<sup>3</sup> *Of life and death, report of the special senate committee on euthanasia and assisted suicide*. Ottawa, ON, Government of Canada, June 1995, page ix.

<sup>4</sup> **Resources reviewed during the development of the 1995 Principles of Practice:**

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<sup>5</sup> Ferris FD, Cummings I. Palliative Care: Towards a consensus in standardized principles of practice. Ottawa, ON: Canadian Palliative Care Association, 1995.

<sup>6</sup> Ferris FD, Balfour HM, Adams D, Hardwick M. How Close are We to Consensus? Ottawa, ON: Canadian Palliative Care Association, 1998.

<sup>7</sup> Farley J, Girard S, Grenier L, Lamontagne C, Langevin J, Lavallée O, Lavoie P, Plante A. Le rapport final. Montréal, QC: Association québécoise de soins palliatifs, 2000. As published in Bulletin "special" de l'Association québécoise de soins palliatifs, February 2001.

<sup>8</sup> Ferris FD, Balfour HM, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. 2001 Proposed Norms of Practice for Hospice Palliative Care. Ottawa, ON: Canadian Palliative Care Association, 2001.

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# A Model to Guide Hospice Palliative Care

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## An Overview of the Model

The model is built on an understanding of health, the illness and bereavement experiences, and the role hospice palliative care plays in relieving suffering and improving quality of life. It was developed to guide both:

- the process of providing care to patients and families through both the illness and bereavement experiences
- the development and function of hospice palliative care organizations.

The guide to the model is divided into five parts:

- I. The underlying understanding of health and illness ([see page 12](#))
- II. The definition of hospice palliative care and the values, principles and foundational concepts that underlie all aspects of hospice palliative care ([see page 17](#))
- III. A guide to the delivery of hospice palliative care to patients and families, including a conceptual framework – the “**Square of Care**” – which ([see page 25](#)):
  - identifies the issues commonly faced by patients and families during an illness
  - identifies the essential and basic steps in the process of providing care
  - presents the principles and norms of practice related to each element of the process of providing care during a clinical encounter
- IV. A guide to organizational development and function, including a conceptual framework – the “**Square of Organization**” – which ([see page 41](#)):
  - identifies the resources required to operate a hospice palliative care organization
  - identifies the principal functions of an organization
  - presents the principles and norms of practice related to each aspect of organizational function
- V. A guide to applying the model to all aspects of hospice palliative care ([see page 53](#))

# I. The Understanding of Health and Illness Underlying the Model

The model for delivering quality hospice palliative care is based on a broad understanding of how people experience health and illness, and how the healthcare system responds to them.

## The Illness Experience

When people become ill, their lives change dramatically. They experience a disease, condition, or aging,<sup>i</sup> and a wide range of issues that are frequently part of their illness experience, including the manifestations of the disease process (e.g., symptoms, functional and psychological changes), and the predicament of how to adjust and continue living under these new circumstances. An illness often leads to changes in roles and relationships. It can result in a number of losses: of opportunity, income, and financial security.<sup>11,12</sup> It can interfere with people participating in experiences that bring meaning and value and add quality to their lives. It can cause suffering and lead everyone to question what the future holds in life and in death.

Most people do not want the changes that come with illness. They perceive these changes to be a threat to their capacity for meaningful and valuable experiences, and to their future. For many, it is the first time they face the fact that they will die at some time in the future.

### Health and Quality of Life

The World Health Organization defines **Health** as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”<sup>1</sup> The state of healthiness is a perception on the part of each individual. In the presence of health, people live their lives in ways that bring them meaning and value. Based on the issues, challenges and opportunities they face, they decide what they like to do, how they will live and run their lives. They decide what will bring them most meaning and value.

David Roy, at the Montréal Research Institute has suggested that **Quality of Life** is: “meaningful and valuable experiences” and “the capacity to have such experiences.”<sup>2</sup> The choices that each person makes and his/her experiences lead to a very personal sense of the quality in life. Quality of life is closely tied to autonomy, and the capacity and right to determine our own future.

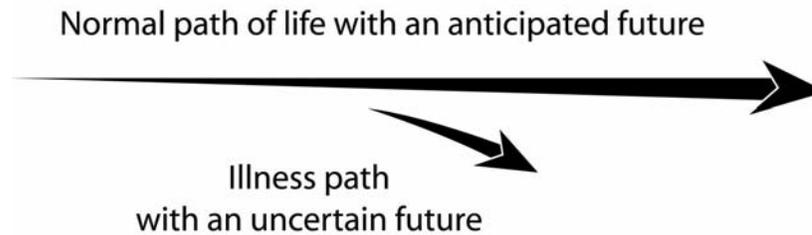
<sup>1</sup> World Health Organization (WHO) Definition of Health, <http://www.who.int/about/who/en/definition.html>.

<sup>2</sup> Ferris FD, Flannery JS, McNeal HB, Morissette MR, Cameron R, Bally G. A Comprehensive Guide for the Care of Persons with HIV Disease. Module 4: Palliative Care. Mount Sinai Hospital & Casey House Hospice, Toronto, Ontario 1995.

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<sup>i</sup> For simplicity, the term “disease” will be used to represent disease, conditions, or aging throughout the document.

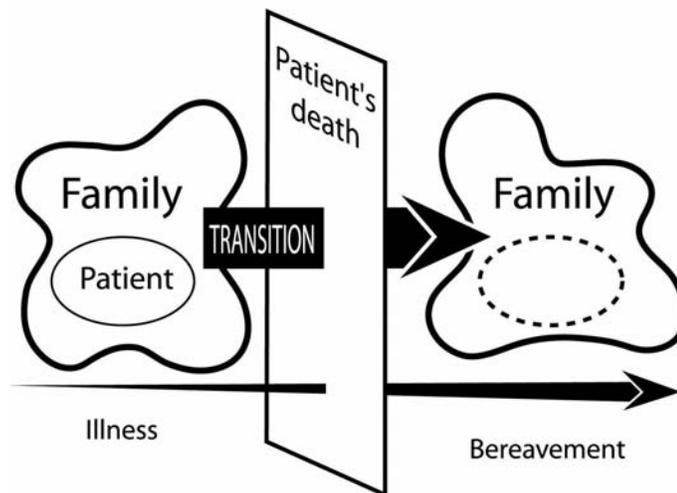
**Figure #4: Divergence from the Path of Life**



### Who is Affected by the Illness?

While a disease affects an individual (the patient), the resulting illness also affects the patient's family (i.e., everyone close in knowledge, care and affection – see page 92), and anyone who lives or works with the patient, or provides care. During the process of an illness, family roles, leadership and group dynamics will be challenged, and even changed. As an advanced life-threatening illness evolves and the patient dies, the existing family group adjourns and a new group forms that will have different membership, roles, leadership and group dynamics. While the patient is no longer present in person, her/his memories and legacies live on and affect everyone.

**Figure #5: Patient and Family**



If the family group can deal with the multiple losses and changes associated with a death, and make the transition through their bereavement experience safely, the survivors will rebuild their lives successfully and reintegrate into society. If the transition is not successful, surviving family members may themselves become patients in the healthcare system, burdens on society, or ineffective employees.

For society, a family's suffering and the quality of their lives is a public health issue. By focusing on relieving suffering and improving quality of life, hospice palliative care aims to promote health – physical, psychological, social and spiritual well-being - in everyone who is affected by

illness and bereavement, including those who provide care. Our success will be a “determinant” of the health of our society in the 21<sup>st</sup> century.<sup>13</sup>

## Multiple Complex Issues

To be effective at relieving suffering and improving quality of life, caregivers must be able to identify and respond to all the complex/multiple issues that patients and families may face.<sup>14,15,16,17,18,19,20</sup> If one or more issues are missed, they can compound one on another. This can lead to increased distress and further complications.

The issues commonly faced by patients and families can be categorized into 8 domains, each of which is of equal importance (see figure #7 on the next page; **Note:** the issues in each domain are examples and not an exhaustive list).

## Associated Expectations

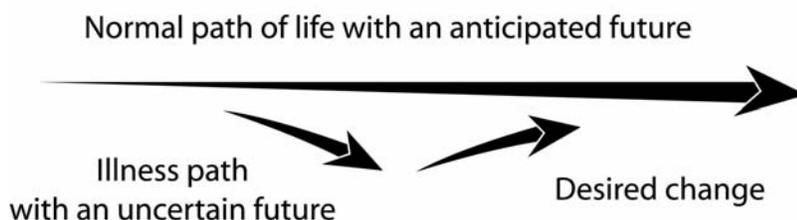
Each issue identified by the patient and family also comes with expectations, needs, hopes and fears. For example: how will the illness affect my relationships with others? What can be done to change the experience and the way it will evolve? How can I restore or maintain my capacity for meaningful and valuable relationships with others for as long as possible?

While each of these issues and its associated expectations, needs, hopes and fears can be challenging and stressful, they can also present opportunities for growth.<sup>21</sup> People may face personal issues they had not recognized before. They may find new approaches to activities of daily living and their roles and relationships. They may develop a new understanding of life, the future, death and dying. They may discover new experiences that are meaningful and valuable in their lives.

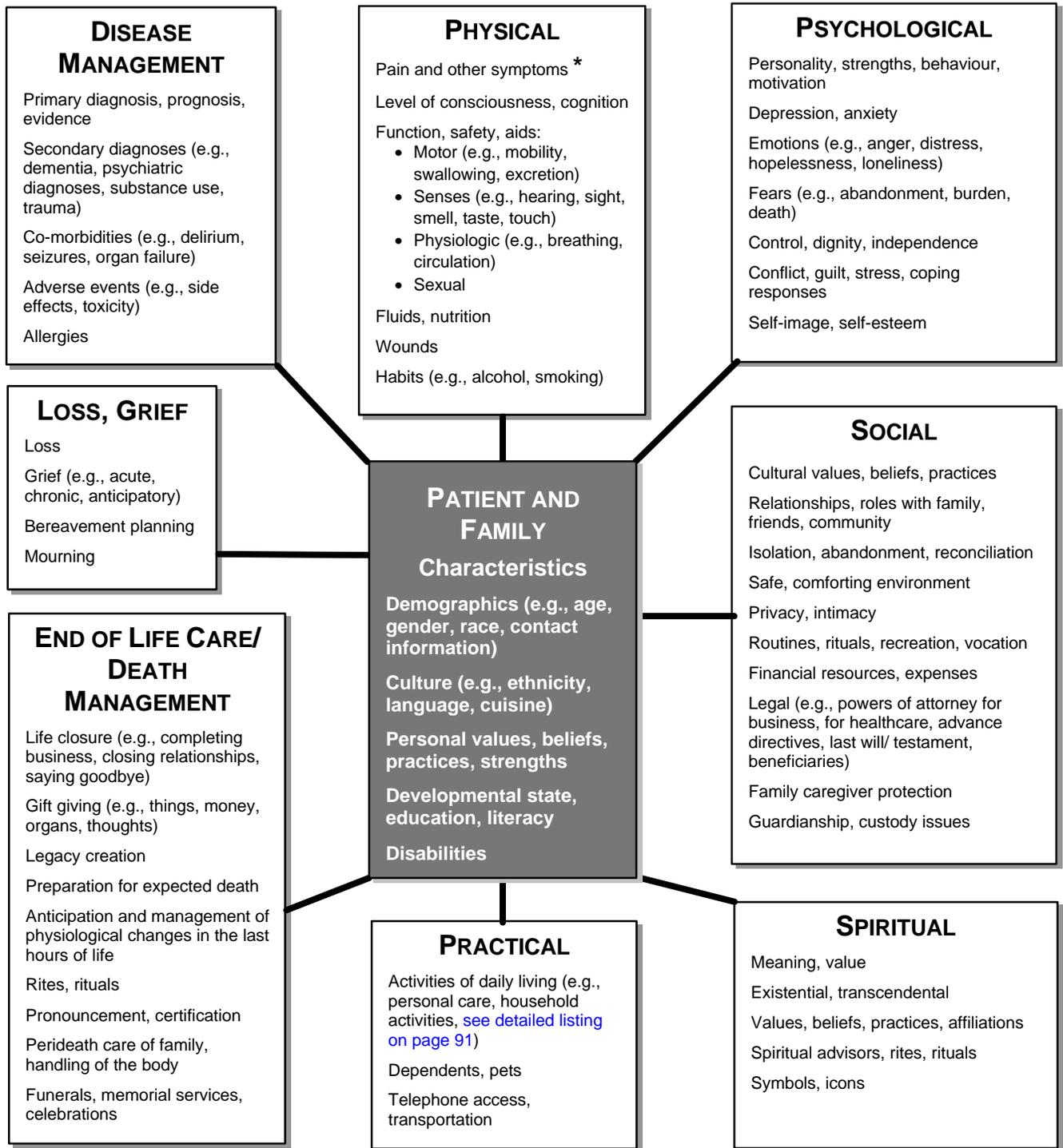
## The Health Care System’s Response

As illness disrupts people’s anticipation of the future, they seek help from the healthcare system to assist them to restore their capacity to live to as close to “normal” as possible. Ultimately, with a combination of appropriate therapeutic interventions aimed at fighting their disease, relieving their suffering and improving the quality of their lives, a patient’s and family’s experience of illness and bereavement may be very different, and their future may be closer to what they anticipated.

**Figure #6: Changing the Experience of Illness**



**Figure #7: Domains of Issues Associated with Illness and Bereavement**



\* Other common symptoms include, but are not limited to:

**Cardio-respiratory:** breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

**Gastrointestinal:** nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

**Oral conditions:** dry mouth, mucositis

**Skin conditions:** dry skin, nodules, pruritus, rashes

**General:** agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

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# II. Hospice Palliative Care: Definition, Values, Principles and Foundational Concepts

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## Definition of Hospice Palliative Care

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

**Hospice palliative care** strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement.

**Hospice palliative care** aims to:

- **treat** all active issues
- **prevent** new issues from occurring
- **promote** opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

**Hospice palliative care** is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care.

**Hospice palliative care** may complement and enhance disease-modifying therapy or it may become the total focus of care.

### The Origins of “Hospice Palliative Care”

Dame Cicely Saunders first conceived of the modern hospice movement in the United Kingdom in the mid 1960s to care for the dying.<sup>1</sup> Balfour Mount coined the term “palliative care” in 1975 so that one term would be acceptable in both English and French as he brought the movement to Canada (from Latin *palliare* = to cloak or cover<sup>2</sup>).

Both hospice and palliative care movements have flourished in Canada, and internationally. Palliative care programs developed primarily within larger healthcare institutions, while hospice care developed within the community as free-standing, primarily volunteer programs. Over time, these programs gradually evolved from individual, grass roots efforts to a cohesive movement that aims to relieve suffering and improve quality of life for those who are living with, or dying from, an illness.

To recognize the convergence of hospice and palliative care into one movement, and their common norms of practice, the term “hospice palliative care” was coined. While hospice palliative care is the nationally accepted term to describe care aimed at relieving suffering and improving quality of life, individual organizations may continue to use “hospice”, “palliative care”, or another similarly acceptable term to describe their organization and the services they are providing.

<sup>1</sup> Saunders C. *A personal therapeutic journey*. *BMJ* 1996; 313(7072): 1599-601.

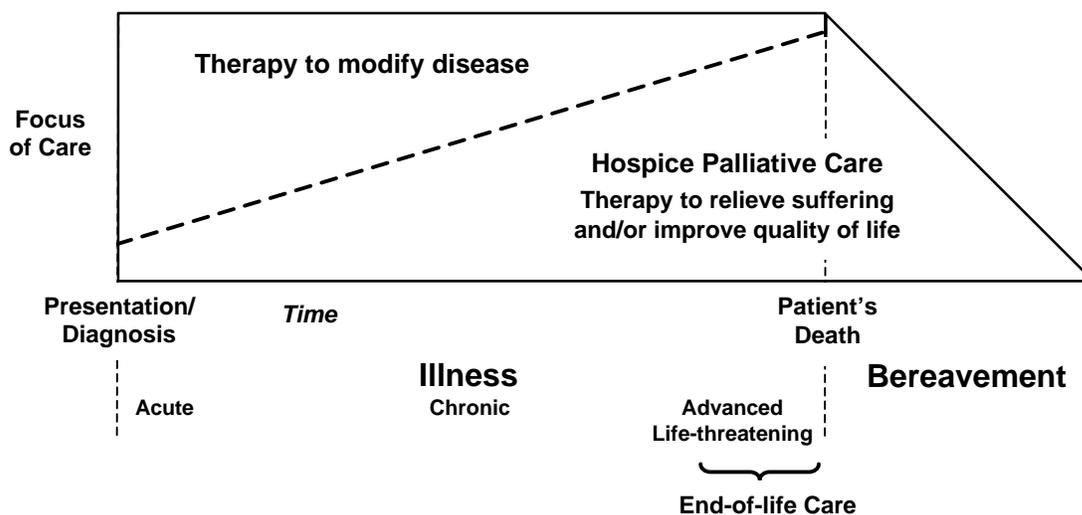
<sup>2</sup> Little W, Fowler HW, Coulson J. *The Shorter Oxford English Dictionary* (Onions CT (ed.)). Toronto, Ontario: Oxford University Press, 1970: 1418.

**Hospice palliative care** is most effectively delivered by an interdisciplinary team of healthcare providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice. These providers are typically trained by schools or organizations that are governed by educational standards. Once licensed, providers are accountable to standards of professional conduct that are set by licensing bodies and/or professional associations.

## The Role of Hospice Palliative Care During Illness

While hospice palliative care has grown out of and includes care for patients at the end of life, today it should be available to patients and families throughout the illness and bereavement experiences. The following figure illustrates the typical shift in focus of care over time.<sup>22</sup>

**Figure #8: The Role of Hospice Palliative Care During Illness**



The top line represents the total 'quantity' of concurrent therapies. The dashed line distinguishes therapies intended to modify disease from therapies intended to relieve suffering and/or improve quality of life (labeled hospice palliative care). The lines are straight for simplicity. In reality, the total 'quantity' of therapy and the mix of concurrent therapies will fluctuate based on the patient's and family's issues, their goals for care and treatment priorities. At times, there may not be any therapy in use at all.

Some aspects of hospice palliative care may also be applicable to patients and families at risk of developing an illness (see the side box on page 53).

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## 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 personal 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.

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## Guiding Principles

The following principles guide all aspects of hospice palliative care:

**GP1. Patient/ Family Focused.** As patients are typically part of a family, when care is provided the patient and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the patient's and family's personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

**GP2. High Quality.** All hospice palliative care activities are guided by:

- the ethical principles of autonomy, beneficence, nonmaleficence, justice, truth-telling and confidentiality<sup>23,24</sup>
- standards of practice that are based on nationally-accepted principles and norms of practice, and standards of professional conduct for each discipline
- policies and procedures that are based on the best available evidence or opinion-based preferred practice guidelines
- data collection/documentation guidelines that are based on validated measurement tools.

**GP3. Safe and Effective.** All hospice palliative care activities are conducted in a manner that:

- is collaborative
- ensures confidentiality and privacy
- is without coercion, discrimination, harassment or prejudice
- ensures safety and security for all participants
- ensures continuity and accountability
- aims to minimize unnecessary duplication and repetition

- complies with laws, regulations and policies in effect within the jurisdiction, host and hospice palliative care organizations.

**GP4. Accessible.** All patients and families have equal access to hospice palliative care services:

- wherever they live
- at home, or within a reasonable distance from their home
- in a timely manner.<sup>i</sup>

**GP5. Adequately Resourced.** The financial, human, information, physical and community resources are sufficient to sustain the organization's activities, and its strategic and business plans. Sufficient resources are allocated to each of the organization's activities.

**GP6. Collaborative.** Each community's needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership.

**GP7. Knowledge-Based.** Ongoing education of all patients, families, caregivers, staff and stakeholders is integral to the provision and advancement of quality hospice palliative care.

**GP8. Advocacy-Based.** Regular interaction with legislators, regulators, policy makers, healthcare funders, other hospice palliative care providers, professional societies and associations, and the public is essential to increase awareness about, and develop, hospice palliative care activities and the resources that support them. All advocacy is based on the Canadian Hospice Palliative Care Association's model to guide hospice palliative care.

**GP9. Research-Based.** The development, dissemination, and integration of new knowledge are critical to the advancement of quality hospice palliative care. Where possible, all activities are based on the best available evidence. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdiction.

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<sup>i</sup> Timelines will be defined by each organization based on its activities.

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# Foundational Concepts

Hospice palliative care is based on three foundational concepts: effective communication, effective group function, and the ability to promote and manage change.

## FC1. Effective Communication

Effective communication is fundamental to both the process of providing care and the function of a hospice palliative care organization. When combined with informed and skilled decision-making, it leads to better care delivery decisions, less conflict, a more effective plan of care, greater patient/family/caregiver satisfaction with the therapeutic relationship, fewer caregiver errors, less stress and fewer burnout/retention problems.

To be effective, hospice palliative caregivers must:

- FC1.1 Share a common language** and understanding of the definitions of the terms they use during the process of providing care; and ensure that commonly used terms are clearly defined, readily available in written format, and integrated into all educational activities. It cannot be assumed that the meaning of critical terms is understood. To assist with effective communication in hospice palliative care, the CHPCA has developed a lexicon of commonly used terms ([see appendices, page 91](#)).
- FC1.2 Use a standard protocol to communicate, and to listen and respond to the reactions** that information creates (e.g., the six-step protocol for effective communication developed by Robert Buckman<sup>25</sup>). An effective protocol to guide communication ensures that information is shared appropriately, and promotes understanding.
- FC1.3 Collect data that documents** the patient's and family's status, and provides a record of each therapeutic encounter. Ensure that data is collected in a manner that is clinically useful, enhances the quality of care, makes it easy to review clinical outcomes and resource utilization, and identify errors and potential risks ([see page 38](#)).
- FC1.4 Educate patients, families and caregivers** using strategies that are built on the principles of adult education, i.e., education should be practical, participatory, considerate of the learners' multiple demands, and include strategies to develop the learners' attitudes, knowledge, skills and behaviours.<sup>26</sup> Patients, families and careteam members will have varying levels of understanding, knowledge and skill with each part of the process of providing hospice palliative care. They will also have different learning styles, and their capacity to learn will diminish when they are under stress. Teaching strategies and supporting materials should include a careful assessment of the learning styles and capabilities of the learners and be planned carefully. Many tools are available to guide formal caregiver education.<sup>27,28,29,30,31</sup>

## FC2. Effective Group Function

All activities related to hospice palliative care revolve around multiple groups that have specific purposes and tasks. Each group is subject to all of the dynamics of group formation and function. As groups develop and mature, they move through a series of stages. One theory of group formation and function suggests that they start by forming and then move through storming and norming until the group begins performing their tasks effectively together (see the side box on page 4). Each participant plays a role. At the end, every group adjourns. Whenever group composition changes, the group must re-establish itself by again moving through the stages until it is performing effectively.<sup>32,33,34</sup>

To be effective, all groups need skilled leadership that facilitates their activities and promotes effective group dynamics.

Groups in hospice palliative care include (see figure #9 on the next page):

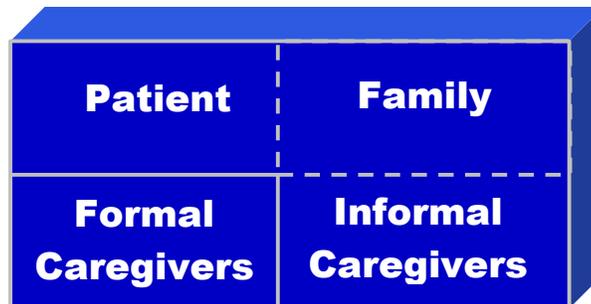
- FC2.1 The patient and family.** Patients typically live in long-standing family groups with well-established group leadership and dynamics (which may or may not be effective). During an illness and bereavement, membership, roles, group dynamics and leadership may change dramatically, particularly as the patient dies, and a new family group forms (see figure #5 on page 13).
- FC2.2 The careteam.** Hospice palliative care is most effectively provided by interdisciplinary careteams. These teams form around individual patient/family units to provide care through a therapeutic relationship. They adjourn when care is no longer needed. Typically, careteams include both formal and informal caregivers, and the patient and family. They require leadership from a formal caregiver who is skilled at group formation/function/dynamics, as well as care delivery. As with any group, it is difficult to establish or maintain a therapeutic relationship if the members are constantly changing.<sup>35</sup>
- FC2.3 Regional teams of formal caregivers.** Most hospice palliative care organizations develop regional teams of formal caregivers to help provide hospice palliative care within a specified geographic region or setting. They work together, share caseloads and discuss cases routinely at regional team meetings. Each formal caregiver may contribute to a number of different patient/family careteams for varying lengths of time.
- FC2.4 The organization's management team(s), committees and workgroups.** Strong and effective group function is also essential to the development of hospice palliative care organizations and their management team(s), committees and workgroups. These groups must function effectively to manage the organization's functions, resources and principal activities.

**Figure #9: Groups in Hospice Palliative Care**

***Patient and Family***



***Careteam***



**FC3. Ability to Facilitate Change**

Hospice palliative care aims to help patients/families manage the challenges and opportunities they face during their changing illness and bereavement experiences. To fulfill that goal, caregivers must be skilled at maximizing openness and adaptability in the attitudes, knowledge, skills and behaviours of everyone involved in the therapeutic relationship. They must also have specific skills to assist patients and families through the transitions they experience during illness and bereavement.

Similarly, all aspects of organizational development and function, education, research and advocacy are also based on the effective application of change strategies.<sup>36</sup>

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## References

URLs were last updated March 23, 2002.

- <sup>22</sup> Adapted from: Expert Working Group on Integrated Palliative Care for Persons with AIDS to Health and Welfare Canada Federal Centre for AIDS. *Caring Together*. Ottawa, ON: Health and Welfare Canada, December 1987: 29.
- <sup>23</sup> [Bioethics for Clinicians, Canadian Medical Association Journal.](#)
- <sup>24</sup> Baker RB, Caplan AL, Emanuel LL, Latham SR. *The American Medical Ethics Revolution*. Baltimore, MD: The Johns Hopkins University Press, 1999.
- <sup>25</sup> Buckman R. *How to Break Bad News: A Guide for Health Care Professionals*. Baltimore, MD: The Johns Hopkins University Press, 1992: 65-97.
- <sup>26</sup> [Ferris FD, von Gunten CF, Emanuel LL. Knowledge: insufficient for change. \*Journal of Palliative Medicine\* 2001, 4\(2\): 145-7.](#)
- <sup>27</sup> [The Ian Anderson Continuing Education Program in End-of-Life Care.](#)
- <sup>28</sup> [The Pallium Project.](#)
- <sup>29</sup> [The Education for Physicians on End-of-life Care \(EPEC\) Project.](#)
- <sup>30</sup> [The End of Life Nursing Education Consortium \(ELNEC\) Project.](#)
- <sup>31</sup> [The End of Life Physician Education Resource Center.](#)
- <sup>32</sup> Tuckman B. Developmental Sequence in Small Groups. *Psychological Bulletin*, 1965; 63: 384-399.
- <sup>33</sup> Tuckman B, Jensen M. Stages of Small Group Development. *Group and Organizational Studies*, 1977; 2: 419-427.
- <sup>34</sup> [McNamara C. \*Group Dynamics: Basic Nature of Groups and How They Work\*. St. Paul, MN: The Management Assistance Program for Nonprofits, 1999.](#)
- <sup>35</sup> Hall P, Weaver L. Interdisciplinary Education and Teamwork: a Long and Winding Road. *Medical Education* 1002; 35: 867-875.
- <sup>36</sup> [von Gunten CF, Ferris FD, Portenoy RK, Glajchen M. \*Change in CAPC Manual: How to Establish a Palliative Care Program\*. New York, NY: Center to Advance Palliative Care, 2001.](#)

# III. The Model to Guide Patient and Family Care

To change their experience of an illness, patients and families seek assistance from healthcare providers who they believe will be knowledgeable and skilled at addressing their issues, expectations, needs, hopes and fears. They are seeking help to:

- identify and assess each of their existing and potential issues, and opportunities for growth
- share information about their illness and bereavement experiences
- establish goals of care
- choose and prioritize therapeutic<sup>i</sup> options that are of potential benefit to them, yet have acceptable risk and burden (to treat existing issues, prevent new ones and promote growth)
- plan their care
- obtain the chosen therapies
- assess the outcomes of the therapeutic interventions.

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## The Process of Providing Hospice Palliative Care

Providing care is a process for creating “wanted” change that is based on:

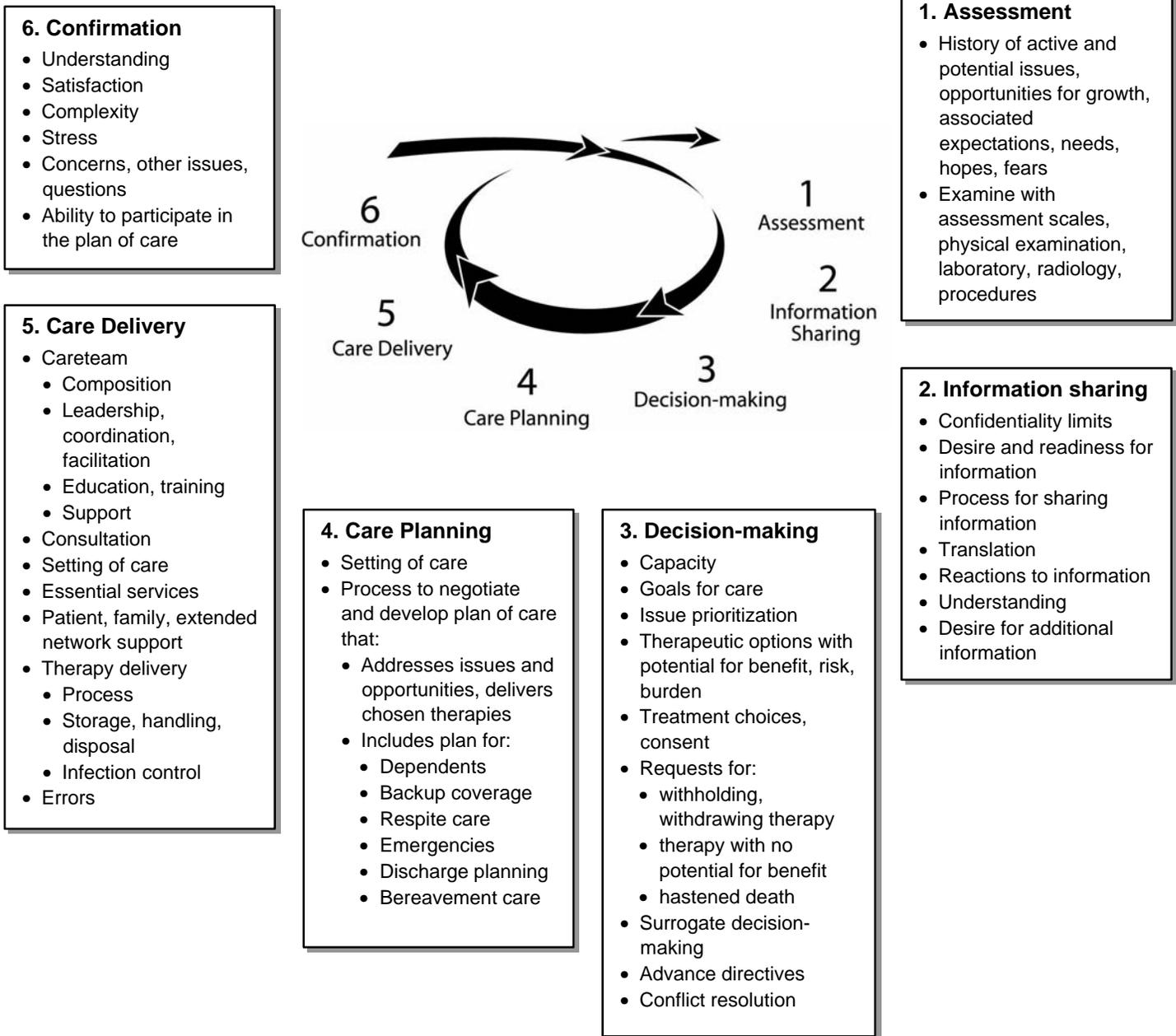
- the development of a therapeutic relationship between those who provide the care (caregivers) and those who receive it (the patient and family as a unit<sup>37</sup>). The relationship evolves with time as familiarity, trust and confidence are established
- a therapeutic process that evolves through a series of therapeutic encounters between the caregivers and the patient and family
- the understanding that only therapies with a potential for benefit and acceptable risk or burden will be offered
- change strategies
- the continued affirmation of the patient’s and family’s values and choices.

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<sup>i</sup> Therapies include medications, counseling, psychotherapy, integrative therapies (acupuncture, aroma, art, chiropractic, imagery, massage, music, recreation, relaxation, touch), other non-pharmacological therapeutics, dressings, equipment, supplies, etc.

During each therapeutic encounter, the process for providing care involves six essential and several basic steps that guide the interaction between caregivers, and the patient and family. While these steps do not need to occur in any specific order, each one must be completed during each encounter.

**Figure #10: Essential and Basic Steps During a Therapeutic Encounter**



## The Square of Care: A Conceptual Framework

The application of the process of providing care (see figure #10 on the previous page) to each of the domains/issues commonly faced by patients and families (see figure #7 on page 15) can be illustrated in the conceptual framework, the “Square of Care” that follows. This tool can serve to guide issue identification and the provision of care during each therapeutic encounter.

**Figure #11: The Square of Care**

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

See page 99 of this guide for the detailed “Square of Care”.

### Elaboration of the Square of Care

Each essential step can be expanded to include all of the details needed to guide the process of providing care, including:

- principles of practice for each essential step (see pages 28-37)
- norms of practice for each basic step (see pages 28-37)
- preferred practice guidelines for each issue (see page 38)
- data collection and documentation guidelines for each issue (see page 38).

All of these details can be placed in the appropriate square in the grid created by the “Square of Care”.

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# Principles and Norms of Practice

For each of the essential and basic steps in the process of providing care, the CHPCA has developed principles and norms of practice.

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## 1. Assessment

### Principles

- P1.1 Assessment guides clinicians to identify and understand each of the issues, risks and opportunities related to the patient's and family's illness and bereavement experiences, and their associated manifestations and predicaments.
- P1.2 Reliable information that is relevant to the patient's and family's situation is gathered from anyone who is able and willing to provide it (e.g., patient, family, friends, formal and informal caregivers – past and present).
- P1.3 The absence of commonly occurring issues is as important as their presence.
- P1.4 Where possible, history-taking and examination techniques and tools are evidence-based.
- P1.5 Assessment is repeated at intervals sufficient to ensure that adequate information is available to guide changes to decision-making and care planning.

### Norms of Practice

- N1.1 Screening questions are used to assess all domains of care and identify all active (unresolved or new) or potential issues and opportunities of importance to the patient, family and caregivers.
- N1.2 History-taking gathers detailed information about:
  - Each identified issue or opportunity (including the disease). This includes:
    - status
    - potential cause
    - associated expectations, needs, hopes and fears
    - perceived benefits and burdens of any previous therapeutic interventions
    - difficulties adhering to therapeutic regimens
  - Adverse events
  - Allergies.

- N1.3 Further information about the status of each identified issue is gathered using a variety of examination techniques, including assessment scales, physical examination, laboratory testing, radiological studies and investigational procedures.
- N1.4 Only examination techniques with the potential to provide beneficial information without undue risk or burden are used.

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## 2. Information-sharing

### Principles

- 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 experiences.
- P2.2 It is the patient's right to choose to be informed about his/her disease, its meaning and implications, available therapeutic options, and their potential benefits, risks and burdens.
- P2.3 Respecting the patient's right to confidentiality:
- families are entitled to information about the patient's disease or condition, available therapeutic options, and their potential benefits, risks and burdens
  - caregivers are entitled to the information they need to provide care effectively.
- P2.4 All communication respects the limits of confidentiality set by the patient.

### Norms of Practice

- N2.1 Limits of confidentiality are defined by the patient before information is shared.
- N2.2 What the patient and family already know, what they would like to know, and whether they are ready to listen is established before sharing information.
- N2.3 Information that is as accurate as possible is shared:
- in a timely manner, as it becomes available
  - only in settings where privacy can be ensured
  - in a language and manner understandable and acceptable to the patient and family.
- N2.4 When language is a barrier, translators who understand the medical concepts and terminology facilitate information sharing.
- N2.5 Emotional and physical reactions to information are assessed regularly and responded to effectively.
- N2.6 The patient's and family's understanding of the shared information, and its implications, is assessed regularly.
- N2.7 The patient's and family's desire for additional information is assessed regularly.

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## 3. Decision-making

### Principles

- P3.1 It is the patient's right to:
- make informed decisions and determine goals for care
  - establish priorities for present and future care from the available appropriate therapeutic options
  - change her/his mind at any time.
- P3.2 The patient:
- must provide voluntary consent to any therapy before it is initiated
  - may request to have any therapy withdrawn at any time
  - may designate an alternate (proxy) decision-maker, and specify when that person will act on his/her behalf (according to the laws in effect in the jurisdiction).
- P3.3 All decision-making processes respect the limits of confidentiality defined by the patient.
- P3.4 Family members are included in decision-making processes whenever possible.

### Norms of Practice

- N3.1 The patient's decision-making capacity is assessed regularly.
- N3.2 The patient's and family's goals for care are assessed regularly.
- N3.3 Requests to withhold or withdraw therapies, requests to initiate therapeutic interventions that appear to have no potential to benefit the patient and family, and requests to hasten death (i.e., euthanasia or assisted suicide), and the factors underlying those requests, are discussed openly.
- N3.4 The patient and family prioritize the importance of each of the identified issues.
- N3.5 The patient is offered therapeutic options to modify the disease, 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.

- N3.6 The patient and family are assisted to select treatment priorities from the options offered, and consent to treatment is obtained.
- N3.7 All patients are asked to designate a proxy decision-maker and specify under what circumstances that person should act.
- N3.8 All patients are asked to provide advance directives to guide the proxy decision-maker should the patient become incapable of making decisions.
- N3.9 When a patient lacks capacity to make decisions, approaches to decision-making are guided by surrogate decision-making legislation and regulations in effect within the jurisdiction.
- N3.10 A process is used to resolve conflict that is acceptable to the patient, family and caregivers.
- N3.11 Therapies, therapeutic options and patient and family choices are reviewed regularly.

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## 4. Care Planning

### Principles

- P4.1 Caregivers respect the patient's choices to have, withhold or withdraw therapeutic interventions.
- P4.2 Care planning takes into account the patient's and family's culture, personalities, emotional status, coping strategies, developmental state and pre-existing psychiatric diagnoses.
- P4.3 Each plan of care is customized, flexible and aims to:
- support the importance, meaning and roles of each person who is involved with the patient and family
  - support the patient's and family's desire for control, independence, intimacy, and their sense of dignity for as long as possible
  - ensure continuity of the plan of care, information and caregivers.

### Norms of Practice

- N4.1 Patients and families are assisted to select an appropriate setting of care.
- N4.2 The plan of care is negotiated and developed with the patient, family and careteam coordinators.
- N4.3 The plan of care includes strategies to:
- address each of the patient's and family's issues or opportunities, expectations, needs, hopes and fears, and deliver their chosen therapies
  - care for dependents (e.g., children, elders, pets)
  - provide backup coverage if caregivers are unable to fill their role in the plan of care
  - provide caregiver respite
  - cope with emergencies
  - plan for discharge
  - provide bereavement care.
- N4.4 The plan and setting of care are reviewed regularly by the careteam and/or the organization's regional team and adjusted to compensate for changes in the patient's and family's status and choices.

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## 5. Care Delivery

### Principles

- P5.1 Care is provided by a specific interdisciplinary careteam that forms to care for each patient/family unit.
- P5.2 Each careteam has the leadership it needs to facilitate careteam formation and function, and coordinate care planning and delivery.
- P5.3 Caregivers have the resources they need to provide care.
- P5.4 Expert consultation is provided in a timely manner whenever it is needed.
- P5.5 All aspects of care are prioritized and delivered in a safe and timely manner, including:
- requests for initial evaluation and ongoing follow-up
  - the implementation of decisions
  - the delivery of chosen therapies, equipment and supplies.
- P5.6 Acute issues are attended to within hours.
- P5.7 Urgent/emergent situations are responded to rapidly.
- P5.8 All care is provided in a manner that
- is respectful of the patient and family and their choices
  - is understandable and acceptable to them
  - maintains their sense of dignity
  - maintains their privacy
  - provides ample opportunity for intimacy.
- P5.9 The patient can be as active in the delivery of care as s/he desires.
- P5.10 There is continuity:
- of the plan of care and information across all settings of care, and among all caregivers and organizations who are involved in the careteam
  - of the caregivers providing care.
- P5.11 For aspects of care not provided by the hospice palliative care organization, partnerships are created with other healthcare providers in order to assist patients and families with all the issues they face.

## Norms of Practice

- N5.1 Each careteam includes (if the patient wishes them to be involved):
- the patient and family
  - the patient's primary care and specialist providers
  - formal caregivers<sup>ii</sup> with the skills needed to implement the plan of care and deliver the chosen therapies
  - informal caregivers who may be family or friends
  - community resources acceptable to the patient and family (e.g., spiritual advisors).
- N5.2 A designated formal caregiver leads, coordinates and facilitates the careteam's activities and function.
- N5.3 An informal caregiver is designated to assist the careteam leader.
- N5.4 Family and friends are educated about their potential role and supported in their decision-making to become informal caregivers.
- N5.5 Informal caregivers receive the orientation, ongoing education and training they need to be competent and confident to provide care.
- N5.6 Informal caregivers are educated about the appropriate use of medications, therapies, equipment and supplies.
- N5.7 Informational resources designed for the informal caregivers support the education they receive.
- N5.8 Informal caregivers have the physical, psychological and spiritual support and assistance they need to provide effective care and ensure their well-being.
- N5.9 Consultants and/or facilitators are engaged as needed to assist the careteam with ethical issues, specialized investigations, therapeutic interventions or activities (e.g., rites and rituals).
- N5.10 The setting of care is maintained so that it is safe, comforting, and provides ample opportunity for privacy and intimacy.<sup>iii</sup>

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<sup>ii</sup> Formal caregivers on the team may include, but are not limited to: chaplains, dietitians, nurses, pharmacists, physicians, psychologists, social workers, speech pathologists, integrative therapists, occupational therapists, physiotherapists, recreational therapists, volunteers.

<sup>iii</sup> Where possible, settings of care are homelike, with access to the outdoors.

- N5.11 Essential services are available 24 hours per day, 7 days per week.
- N5.12 The patient, the family, and their network of extended family, friends and community are:
- educated about the appropriate use of medications, therapies, equipment and supplies so they will understand what is happening and why
  - supported so they will be able to maintain their own well-being, adapt to the ongoing changes that are taking place, and support each other.
- N5.13 All therapeutic interventions are delivered in a safe and timely manner that:
- is consistent with the organization's standards of practice and policies and procedures
  - optimizes their potential for benefit
  - minimizes the potential for medication interactions, adverse effects or burden
  - is consistent with manufacturer's/supplier's instructions
  - is acceptable to the patient and family.
- N5.14 No medications are mixed if their compatibility is not known.
- N5.15 All medications, equipment and supplies are stored and maintained so that they are stable and safe for use.
- N5.16 All potentially hazardous materials, including toxic or controlled medications, biological substances and equipment or supplies (e.g., sharps) are stored, handled and disposed of safely.
- N5.17 No medications or supplies are used that are damaged or outdated.
- N5.18 No equipment is used that is in need of repair, or is outdated.
- N5.19 An infection control program guides all clinical activities.
- N5.20 Any errors in therapy delivery are reported to supervisors immediately.
- N5.21 Appropriate antidotes are started as quickly as possible.
- N5.22 Any error is discussed openly with the patient or surrogate decision-maker and/or relevant family.
- N5.23 Errors are documented appropriately.
- N5.24 All approaches to delivering care are reviewed regularly and adjusted to compensate for changes in the patient's and family's status and choices.

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## 6. Confirmation

### Principles

- P6.1 Overall understanding, satisfaction, sense of complexity, level of stress, concerns, questions and desire for additional information are assessed during each therapeutic encounter.

### Norms of Practice

- N6.1 By the end of each therapeutic encounter, the formal caregiver assesses and reinforces the patient's, family's and informal caregiver's understanding of:
- the situation
  - the plan of care
  - the appropriate use of medications, therapies, equipment and supplies.
- N6.2 By the end of each therapeutic encounter, the formal caregiver assesses the patient's, family's and informal and formal caregivers':
- satisfaction with the process of providing care and their overall situation
  - perception of the complexity of the situation
  - perception of the level of stress
  - concerns, questions and desire for additional information
  - ability to provide and participate in the plan of care.

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## Preferred Practice Guidelines

Preferred practice guidelines that are based on the best available evidence or opinion are used to develop issue-specific policies and procedures. While the CHPCA consensus-building process has not engaged in the development of preferred practice guidelines, a number of resources are available on the Internet.<sup>38</sup>

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## Data Collection/Documentation Guidelines

Data collection/documentation guidelines that are based on validated measurement tools are used to develop issue-specific standards for data collection and documentation, paper and electronic health records, and population data surveillance strategies. While the CHPCA consensus-building process has not engaged in the development of data collection/documentation guidelines, some principles guiding data collection are outlined below.

### Principles Guiding Data Collection

During each therapeutic encounter, data collection and documentation aim to record:

- the presence or absence of each commonly-occurring issue
- the status at a “point in time” of each active issue
- what was done during the encounter.

The data collected must be clinically useful. The task of collecting data must be practical, not burdensome. The data must be collected in a format that is easy to review as part of the quality management activities, and readily identifies errors and risks. Documentation that an issue is absent is as important as documenting that it is present. Absence of any documentation related to an issue suggests that it was not assessed. If the process used during the encounter followed accepted policies and procedures, only the status and outcomes of the process need to be documented. If the process varied from accepted policies and procedures, it should be documented as well.

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## References

**URLs were last updated March 23, 2002.**

<sup>37</sup> Kristjanson LJ. The family as the unit of treatment. In Portenoy R, Bruera E (eds). *Topics in Palliative Care*. New York, NY: Oxford University Press, 1997; 1: 245-261.

<sup>38</sup> **Preferred Practice Guideline Resources on the Internet:**

[A Comprehensive Guide to the Care of Persons with HIV/AIDS.](#)

[A Guide to End-of-Life Care for Seniors.](#) Fisher R, Ross MM, MacLean MJ.

[Canadian Medical Association Clinical Practice Guidelines.](#)

[Compendium of Guidelines and Position Statements.](#) Phillips DF, Sabatino C, Long KN. Washington, DC: Last Acts, 2001.

[Edmonton Regional Palliative Care Program.](#)

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[Multicultural Palliative Care Guidelines.](#) Taylor A, Box M. Palliative Care Council of South Australia, Inc., 1999.

[National Guideline Clearinghouse, Agency for Healthcare Research and Quality \(US\).](#)

[National Hospice and Palliative Care Organization, Alexandria, VA, USA.](#)

[Pain and Policy Studies Group, University of Wisconsin Comprehensive Cancer Center.](#)

[Palliativedrugs.com.](#)

[The Cochrane Library.](#)

Search [Google.com](#) for Guidelines related to Hospice or Palliative Care

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## Notes

# IV. The Model to Guide Organization Development and Function

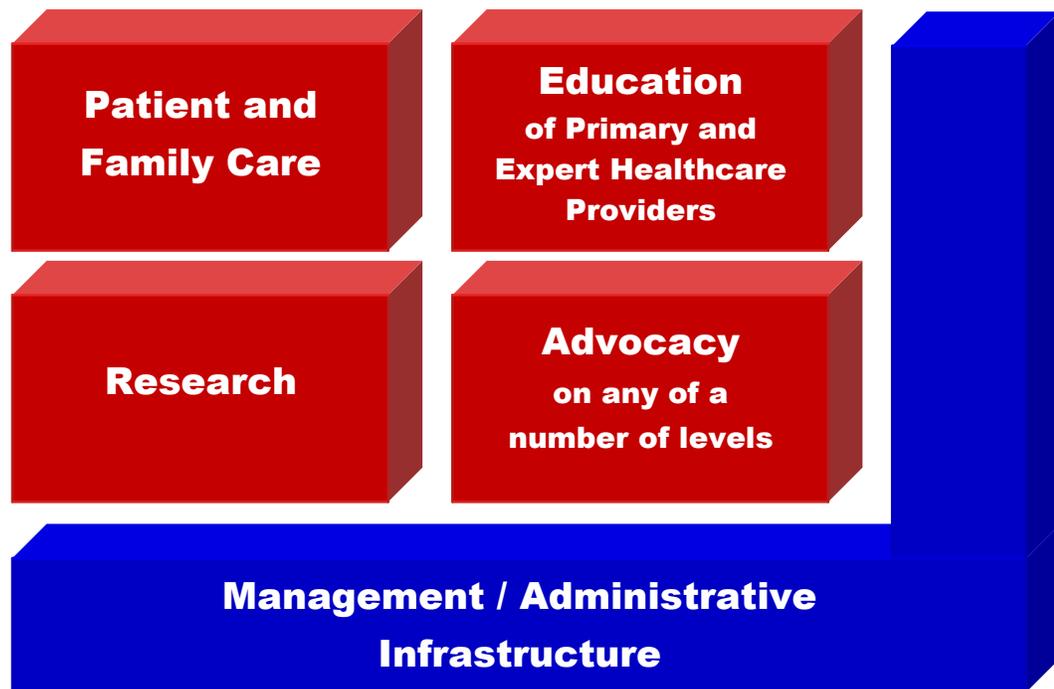
While the model presented in this section will focus on the development and function of a hospice palliative care organization, the concepts are applicable to any group with a task (e.g., a careteam, a regional interdisciplinary team, a committee or workgroup, and families).

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## The Nature of Hospice Palliative Care Organizations

Hospice palliative care organizations are typically in the 'business' of one or more principal activities or 'product lines'. To support these principal activities, each organization must have a management and administrative infrastructure to develop and maintain the resources needed to operate principal activities, and oversee the program's principal functions.

**Figure #12: The Principal Activities of Hospice Palliative Care**



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## Mission and Vision Statements

To help identify/define their activities and functions, organizations usually begin by developing a mission and a vision statement. The CHPCA consensus-building process has developed sample mission and vision statements for a hospice palliative care organization.

### Sample Mission Statement

A mission statement is a short statement of an organization's purpose (i.e., what it is and what it does). Each organization will create a very personalized mission statement during its strategic planning process. A mission statement might look like:

"The (named) program provides hospice palliative care services and education to all patients and families within (named geographic region or health care district)."

### Sample Vision Statement

A vision statement is a short statement of an organization's aspirations (i.e., what it hopes to become and achieve in the future). Each organization will create a very personalized vision statement during its strategic planning process. A vision statement might look like:

"The (named) program will be the leading hospice palliative care program providing clinical services to all patients and families within (named geographic region or health care district) consistent with the Canadian Hospice Palliative Care Association's National Norms of Practice. The (named) program will be a leader in hospice palliative care education and research."

## Resources

To achieve its mission and vision, deliver its principal activities and maintain its infrastructure, a hospice palliative care organization must develop and maintain a number of key resources.

**Figure #13: Resources to Support Hospice Palliative Care**

Financial Resources	Human Resources	Information Resources	Physical Resources	Community Resources
Assets <ul style="list-style-type: none"> <li>• Cash</li> <li>• Capital</li> <li>• Investments</li> <li>• Receivables</li> </ul> Liabilities <ul style="list-style-type: none"> <li>• Payables</li> <li>• Depreciation</li> <li>• Taxes</li> </ul> Insurance	Formal caregivers <ul style="list-style-type: none"> <li>• Bereavement counselors</li> <li>• Chaplains</li> <li>• Dietitians</li> <li>• Integrative therapists</li> <li>• Nurses</li> <li>• Occupational therapists</li> <li>• Pharmacists</li> <li>• Psychologists</li> <li>• Physicians</li> <li>• Physiotherapists</li> <li>• Psychologists</li> <li>• Social workers</li> <li>• Speech pathologists</li> <li>• Support workers</li> <li>• Volunteers (caregivers)</li> <li>• Consultants (e.g., ethics, clinical, legal, administrative)</li> </ul> Staff <ul style="list-style-type: none"> <li>• Administration</li> <li>• Support</li> </ul> Volunteers (non-caregivers)	Records <ul style="list-style-type: none"> <li>• Health</li> <li>• Financial</li> <li>• Human resource</li> <li>• Assets</li> </ul> Resources <ul style="list-style-type: none"> <li>• Resource, reference materials, (e.g., books, journals)</li> <li>• Internet, Intranet</li> </ul> Resource directory	Environment <ul style="list-style-type: none"> <li>• Space</li> <li>• Lighting</li> <li>• Heating, cooling</li> <li>• Utilities</li> <li>• Parking</li> </ul> Equipment <ul style="list-style-type: none"> <li>• Medical</li> <li>• Diagnostic and investigative</li> <li>• Office</li> <li>• Communication systems, (e.g., telephones, pagers, e-mail)</li> <li>• Information technology systems, (e.g., computers, printers, networks, internet access)</li> <li>• Security systems</li> </ul> Materials, Supplies <ul style="list-style-type: none"> <li>• Medical</li> <li>• Office</li> <li>• Other</li> </ul>	Host organization Healthcare system Partner healthcare providers Community organizations Faith/religious communities Stakeholders Public

## Principal and Basic Functions

To develop its resources and provide its principal activities, a hospice palliative care organization must implement five principal and a number of basic functions.

**Figure #14: Hospice Palliative Care Principal and Basic Functions**

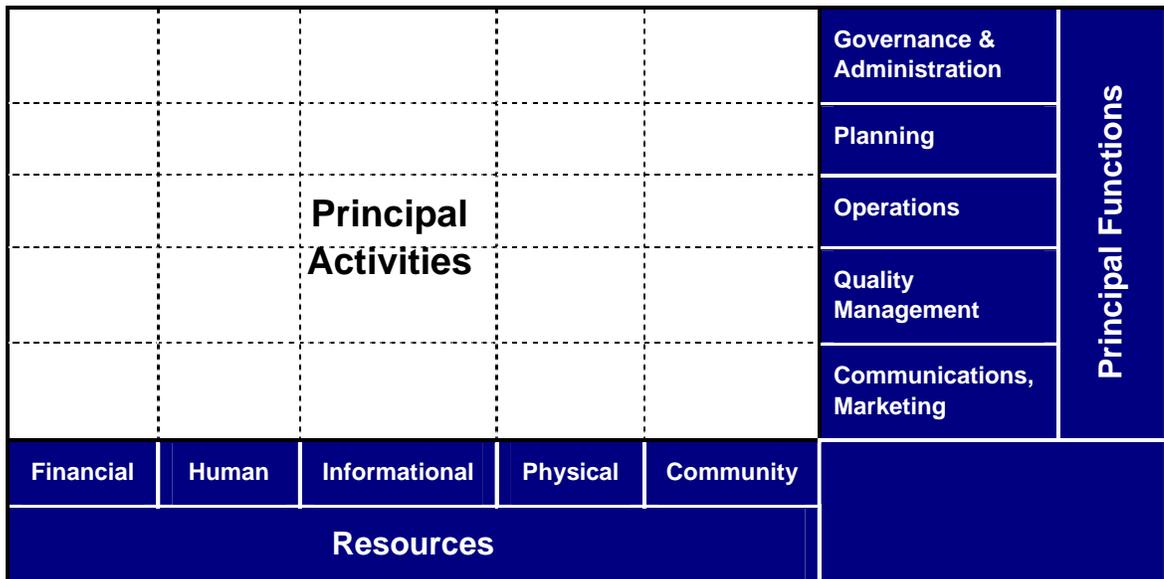
Governance and Administration	Planning	Operations	Quality Management (Evaluation)	Communications/Marketing
<p>Leadership</p> <ul style="list-style-type: none"> <li>• Board</li> <li>• Management</li> </ul> <p>Organizational structure/ accountability</p>	<p>Strategic plan</p> <ul style="list-style-type: none"> <li>• Needs assessment</li> <li>• Mission, vision</li> <li>• Values, purpose, principal activities</li> <li>• Goals, objectives, strategies, tactics</li> <li>• Timelines, strategic decision points</li> </ul> <p>Business plan</p> <ul style="list-style-type: none"> <li>• Organizational/ accountability structure</li> <li>• Resource acquisition and management</li> <li>• Implementation</li> <li>• Quality management</li> <li>• Communications, marketing</li> </ul> <p>Business development</p>	<p>Standards of practice, policies and procedures, standards for data collection/documentation</p> <p>Resource acquisition and management:</p> <ul style="list-style-type: none"> <li>• Fund development – stewardship, annual program, foundation and research grants, planned giving</li> <li>• Financial resources - billing, accounting, banking, dispersement</li> <li>• Human resources - recruitment/retention, credentialing, orientation, education, evaluation, staffing, support, recognition, incentives, occupational risk/stress, critical incident debriefing and support, self-actualization and spiritual growth, termination, outplacement</li> <li>• Informational resources - data collection, purchasing, storage, maintenance, reporting, destruction</li> <li>• Physical resources - purchasing, stock control, maintenance, disposal</li> <li>• Community resources - relationship building, contracting, relationship management, contract/ relationship termination</li> </ul> <p>Safety, security, emergency systems</p>	<p>Performance improvement</p> <ul style="list-style-type: none"> <li>• Outcomes</li> <li>• Resource utilization</li> <li>• Adverse events, including errors, complaints</li> <li>• Satisfaction</li> </ul> <p>Routine review</p> <ul style="list-style-type: none"> <li>• Utilization review, clinical outcomes and resource utilization</li> <li>• Risk management</li> <li>• Compliance</li> <li>• Caregiver and employee satisfaction</li> <li>• Community needs</li> <li>• Financial audit</li> <li>• External accreditation</li> <li>• Strategic and business plans</li> <li>• Standards of practice, policies and procedures, standards for data collection/documentation</li> </ul>	<p>Communication and marketing strategies</p> <p>Materials</p> <p>Support for fundraising</p> <p>Media liaison</p> <p>Adverse situations</p>

## Square of Organization: A Conceptual Framework

The application of an organization's principal functions to the management of its resources can be illustrated by the conceptual framework: the "Square of Organization". Like the "Square of Care," this framework can be used as a tool to guide the development, function and review of the organization's infrastructure, and each of its principal activities.

The "Square of Organization" can also be used to guide the development, function and review of any group with a task (e.g., careteams, regional teams, committees, workgroups).

**Figure #15: The Square of Organization**



See page 102 of this guide for the detailed "Square of Organization".

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## Principles and Norms of Practice

For each of the principal and basic functions of an organization, the CHPCA has developed principles and norms of practice. (The numbering continues from the principles and norms of practice in the previous section.)

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## 7. Governance and Administration

### Principles

- P7.1 Governance and administration are essential to the development, implementation, operations and accountability of hospice palliative care organizations.
- P7.2 Governance includes senior leadership and representatives of the host organization(s), community, formal and informal caregivers, patients and families.

### Norms

- N7.1 The board and senior management guide the organization's development and function.
- N7.2 The organizational structure supports all of the organization's activities and defines internal accountability.

---

## 8. Planning

### Principles

- P8.1 The strategic planning process defines the organization's mission, vision, values, purpose/activities and developmental directions.
- P8.2 The business planning process defines the resources and functions that will be needed to implement the strategic plan.

### Norms

- N8.1 The organization has a strategic plan to guide the development of the organization's infrastructure and principal activities. The strategic plan includes:
- a needs assessment
  - mission and vision statements
  - values, principles, principal activities and service delivery models of the organization
  - developmental goals, objectives, strategies and tactics for developing the organization
  - timelines and strategic decision-points during development.
- N8.2 The organization has a business plan to guide the development of the resources and functions it will need to support its infrastructure and principal activities. The business plan includes:
- a governance and administrative structure
  - a plan(s) to acquire/manage each of the needed resources
  - a plan to implement each of the principal activities and the infrastructure
  - a quality management plan
  - a communications/marketing plan.
- N8.3 The business development plan is congruent with the overall strategic plan for the organization.

---

## 9. Operations

### Principles

- P9.1 Standards of practice, policies and procedures, and data collection/ documentation guidelines guide all of the organization's activities.
- P9.2 Individuals within the organization are also guided by the standards of professional conduct for their discipline.
- P9.3 Data and documentation record all of the activities of the organization.
- P9.4 Adequate financial resources are essential to support the organization's activities and ensure its long-term viability.
- P9.5 Adequate staff, who are appropriately trained and receive continuing hospice palliative care education and evaluation are essential for the organization to develop its infrastructure and principal activities.
- P9.6 Ongoing support to ensure the staff's physical, psychological and spiritual well-being is integral to the provision of hospice palliative care.
- P9.7 Readily accessible records and information resources are integral to the provision of hospice palliative care.
- P9.8 Adequate physical resources are integral to the provision of hospice palliative care.
- P9.9 Safety, security and emergency systems are essential to ensure the integrity of the organization.

### Norms of Practice

- N9.1 The organization uses the CHPCA norms of practice to guide the development of its standards of practice.
- N9.2 The organization uses the best available preferred practice guidelines, which are ideally based on evidence or expert opinion, to guide the development of its policies and procedures.
- N9.3 The organization uses validated or the best available measurement tools to guide the development of its data collection/ documentation guidelines.
- N9.4 The organization has sufficient financial resources to support its activities and meet its strategic and business goals.

- N9.5 Fundraising activities and stewardship are consistent with the mission, vision and values of the organization.
- N9.6 The organization has policies and procedures to guide fundraising, stewardship, budgeting, billing, accounting, banking, and disbursement of funds (including expenses, salaries/benefits, and taxes).
- N9.7 The organization has sufficient human resources<sup>i</sup> to support its activities.
- N9.8 The organization has policies and procedures to guide staff recruitment and retention, credentialing, orientation and education, staff support, staffing, incentive/recognition programs, and employment termination/outplacement.
- N9.9 The organization's staff and volunteers reflect the cultural diversity of the community it serves.
- N9.10 There are ongoing programs to orient, train, support and ensure the competency of the formal caregivers, including volunteers, and other employees.
- N9.11 Formal caregivers' understanding of the appropriate use of medications, therapies, equipment and supplies is checked and reinforced regularly.
- N9.12 Formal caregivers have the knowledge and support they need to be able to respect the personal boundaries that are an integral part of effective therapeutic relationships.
- N9.13 The employees and volunteers are satisfied with the support they receive from the program.
- N9.14 There are ongoing programs to address employee issues and improve satisfaction with their work lives.
- N9.15 There are incentive/recognition programs in place that support the activities of the program and reward exceptional service.
- N9.16 There are continuous efforts to identify and minimize occupational risks and stresses.
- N9.17 The organization has sufficient information resources to support its activities.
- N9.18 The organization has policies and procedures to guide purchasing, storage, maintenance and disposal of information resources and resource directories.
- N9.19 The organization has policies and procedures to guide the collection, storage, reporting and destruction of its health, financial, human resource and asset records.

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<sup>i</sup> Human resources include formal caregivers (including caregiving volunteers), consultants, management and support staff, and non-caregiving volunteers.

- N9.20 The health records needed to support care delivery and quality management are readily accessible.
- N9.21 The library and other information resources needed to support orientation, education, training and other activities are readily accessible.
- N9.22 New knowledge is disseminated in a timely manner to the appropriate individuals within the organization, and where appropriate, it is integrated into day-to-day activities.
- N9.23 The organization has sufficient physical resources to support its activities.
- N9.24 The organization has policies and procedures to guide purchasing, stock control, maintenance and disposal of its physical resources.
- N9.25 The organization has sufficient community resources to support its activities.
- N9.26 The organization has policies and procedures to guide the development and maintenance of its formal relationship with community resources.
- N9.27 The safety, security and emergency systems support all aspects of the organization's activities.

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## 10. Quality Management (Evaluation)

### Principles

- P10.1 Ongoing evaluation improves the quality of the organization's activities.
- P10.2 The quality management process regularly reviews all aspects of the organization's activities, resources and functions to assess their effectiveness, and revise them.
- P10.3 Compliance with all legislation, regulations and policies governing hospice palliative care is essential.

### Norms of Practice

- N10.1 The organization has an ongoing program to improve its performance using routine measures of outcomes, resource utilization, adverse events (e.g., medication and other therapeutic errors, complaints), and stakeholder satisfaction.
- N10.2 The organization:
- regularly reviews the outcome and resource utilization data for its patients and families, its careteams, its regional teams, the organization, and the population it serves
  - has a risk management program, and a process to review and respond to complaints
  - has a compliance review program to ensure that it is in compliance with legislative and regulatory mandates
  - has an ongoing program to evaluate and improve caregiver and employee satisfaction with their work lives
  - regularly assesses its customers and community to see if their expectations and needs for hospice palliative care are being met, and whether they are satisfied
  - audits its financial records annually
  - participates in intermittent accreditation reviews to assess its effectiveness compared to other similar organizations, and the CHPCA norms of practice.
- N10.3 The organization has a process to regularly review and update its strategic and business plans.
- N10.4 The organization has a process to regularly review and update its standards of practice, policies and procedures, and data collection/ documentation guidelines.

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## 11. Communications/Marketing

### Principles

- P11.1 Communications and marketing increases awareness of the organization, and facilitates access to its activities.

### Norms

- N11.1 The organization has both internal and external communication and marketing initiatives to disseminate information about its clinical services and other activities, raise awareness of them, and increase use of its services.
- N11.2 Materials are written and presented in a manner appropriate to their intended audiences.
- N11.3 Information about the organization, its activities, and how to access its services is readily available to patients, families, caregivers, and the public.
- N11.4 The organization has a communication strategy to support its fundraising.
- N11.5 The organization has a plan for media liaison.
- N11.6 The organization has a plan for communication in the event of an adverse situation.

# V. Application of the Model

The consensus-based model presents the ideal of what hospice palliative care should be, independent of funding and service delivery models. It was developed to guide the delivery of patient and family care and the function of hospice palliative care organizations. The concepts can also be applied to all other aspects of hospice palliative care, including education, quality management research and advocacy. While the model was developed in Canada, with slight modification to local circumstances, it has broad international application.

This chapter describes briefly how the model can be applied by:

- both primary and expert clinicians to guide the process of providing hospice palliative care, the timing of referrals for consultation with hospice palliative care experts, and the development of standards of practice, policies and procedures, and standards for data collection/documentation
- administrators to guide the process of developing an organization, standards of practice, policies and procedures and standards for data collection and documentation
- careteam leaders to guide the process of developing individual patient/family careteams
- quality managers to guide the development of a comprehensive quality management strategy
- educators to guide the development of core competencies, curricula and examinations for primary and expert hospice palliative care providers
- regulators, policy makers and funders to guide the review and development of laws, regulations, policies, funding, service delivery, and population data surveillance strategies
- researchers to ensure that research focuses on the deficits in our knowledge and skills about hospice palliative care practice
- consumer and provider advocates to guide the understanding of hospice palliative care services, the expectations of healthcare providers, and their advocacy efforts.

While hospice palliative care has grown out of “care for the dying”, the concepts can now be used to guide care at any point during an acute, chronic, or life-threatening illness, or bereavement.

Certain aspects of hospice palliative care – such as effective communication and decision-making, advance care planning, surrogate decision-making, information about what to expect during an illness and what to expect from healthcare providers, and the management of symptoms, loss, grief and transitions – can also be used effectively with those who are at risk of developing an illness (e.g., people who are HIV-positive, those with genetics that put them at risk of developing a life-threatening illness, the elderly, and even people who are well but worried that they will develop an illness in the future).

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## The Integrated Square of Care and Organization

There are two main aspects of the CHPCA model to guide hospice palliative care: the delivery of patient and family care, and the development and function of an organization. Although for presentation purposes these have been separated in this monograph, the two are inextricably linked. They are guided by the same understanding of the illness and bereavement experiences, the same definitions, values, principles and foundational concepts. They are also interdependent. Clinicians cannot provide care without the resources and principal functions of an organization, and the organization cannot fulfill its mission or vision without a well-established process of providing care that addresses the issues commonly faced by patients and families. This interrelationship between patient and family care and hospice palliative care organizational function is illustrated by the integrated “Square of Care and Organization” in the figure below. In essence, the organizational resources and functions are present to “support” the clinical activities.

**Figure #16: Interrelationship of the Square of Care and the Square of Organization**



Adaptations of this tool can be used to guide all activities related to hospice palliative care. A simple version is shown in [figure #17](#) on the next page.

Figure #17: The Square of Care and Organization

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

See page 100 and 101 of this guide for the detailed “Square of Care and Organization.”

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# 1. Applying the Model to Clinical Care

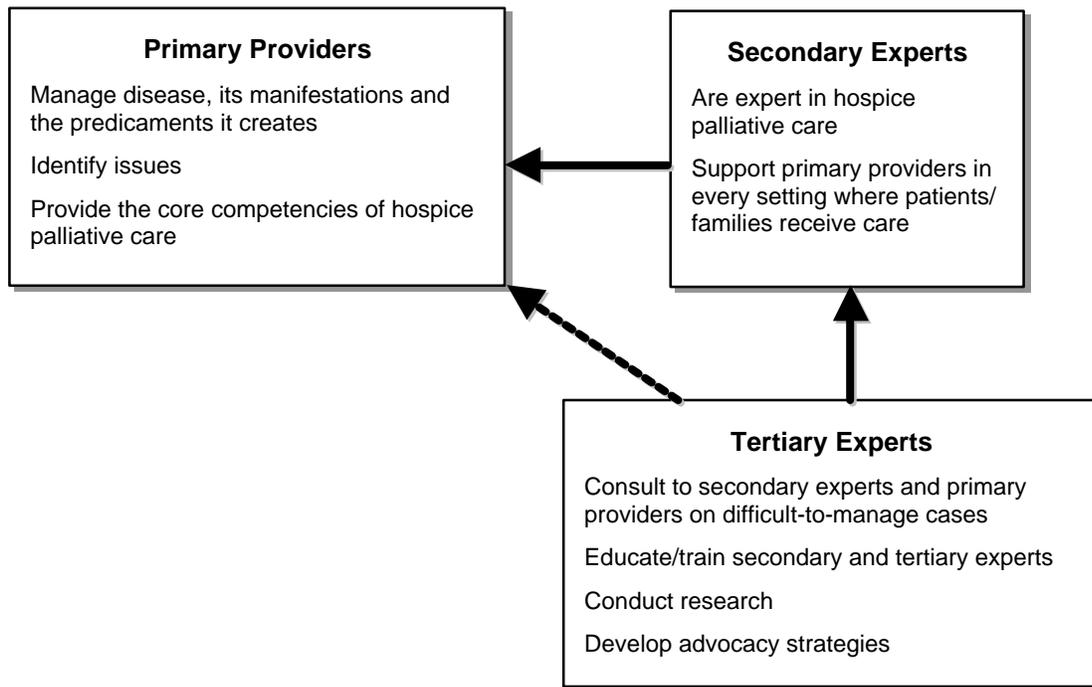
## Providing Hospice Palliative Care

Because hospice palliative care issues occur throughout the illness and bereavement experiences, all clinicians (i.e., formal caregivers including volunteers) must be:

- competent at identifying the full range of issues that patients and families commonly face
- skilled at providing the core competencies of hospice palliative care using approaches that are based on widely-accepted preferred practice guidelines
- effective at assessing their outcomes
- appropriate with their documentation.

As in any other healthcare situation, when primary providers encounter care issues and situations beyond their level of confidence and expertise, or when their practice outcomes are not consistent with accepted norms of practice (i.e., those in this model), they must be able to seek help and support from hospice palliative care experts.<sup>39</sup> For this to be possible, interdisciplinary teams of secondary hospice palliative care experts must be readily accessible in every setting where patients and families receive care. In addition, these secondary hospice palliative care experts require access to tertiary experts in every major academic/population centre.

**Figure #18: Provider Roles in Hospice Palliative Care**



## The Development of a Therapeutic Relationship

Hospice palliative care is based on the development of a therapeutic relationship between skilled caregivers and the patient/family. It is a creative process that aims to change the patient's and family's experience of illness and bereavement. It combines the art and science of the process of providing care with the knowledge and skills needed to deliver a wide range of therapeutic interventions.

Each relationship builds over a series of successive therapeutic encounters. Individual therapeutic encounters must occur with sufficient frequency to address the changes in the patient's/family's situation, and deliver the chosen therapies. For some patients, circumstances may require prolonged encounters or continuous care.

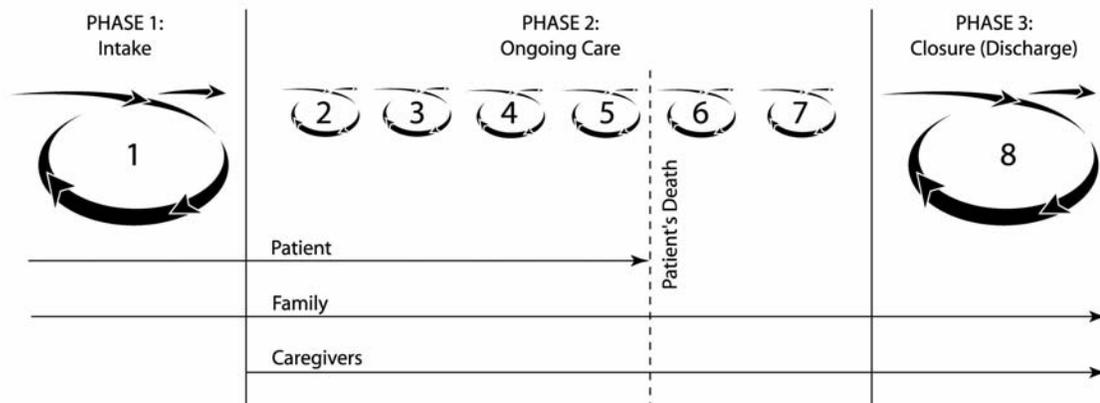
Development of an effective therapeutic relationship depends on formal caregivers being:

- skilled at effective communication (see page 21)
- skilled at facilitating careteam formation and function (see page 22)
- effective change agents (see page 23).

To develop a successful therapeutic relationship requires continuity of both the formal and informal caregivers throughout the process. Every time caregivers change, the process of developing a therapeutic relationship will start over and move through the stages of group development until the patient, family and caregivers are again performing effectively together.

Both primary and expert hospice palliative care providers will find the details of the six essential and several basic steps (see figure 10 on page 26) and the conceptual framework the "Square of Care" (see figure 11 on page 27), useful to guide any of their therapeutic encounters.

**Figure #19: Successive Encounters During the Development of a Therapeutic Relationship**



**Note:** the numbers in the figure only serve to highlight the sequence of encounters. Depending on the need for care, and the length of involvement, there may be more or fewer encounters over the duration of the therapeutic relationship.

## Phases of a Therapeutic Relationship

The development of a therapeutic relationship can be thought of as having 3 phases: intake, ongoing care, and closure (discharge). Depending on the phase of the therapeutic relationship and who is present during a given therapeutic encounter, there will be variability in the specific content and approach to care for each essential step.

### Assessment

During assessment, clinicians can use the list of domains and common issues to guide a functional inquiry and identify issues (see figure #7 on page 15). A validated screening tool, such as NEST,<sup>40</sup> can guide clinicians to domains in which there are active issues that require a more detailed history and examination. Clinicians must also look for issues that could become problems if they are not prevented, and opportunities for growth. If one or more issues are missed, they can compound and further complicate the patient/family situation. See figure #20 for variations in the approach to assessment during each phase of a therapeutic relationship.

**Figure #20: Variation in Assessment by Phase of Relationship**

Phase 1: Intake	Phase 2: Ongoing care	Phase 3: Closure (Discharge)
Collect patient/family characteristics/contact information Collect history of primary and secondary diseases, comorbidities and their treatments Establish prognosis Assess eligibility for admission, if there are entry criteria (e.g., Conditions of Participation, Medicare Hospice Benefit <sup>41</sup> ) Conduct a comprehensive functional inquiry to screen all domains for active and potential issues, and opportunities for growth Conduct a detailed history and examination of all identified issues Establish preferences patient/family have for the overall "process to provide care" Establish whether last will/named beneficiaries exist Establish preparedness to discuss end of life/death Collect specific data, including: <ul style="list-style-type: none"> <li>• cultural, personal, religious values, beliefs, practices</li> <li>• developmental state</li> <li>• disabilities</li> <li>• adverse events</li> <li>• allergies</li> <li>• adherence to past therapeutic interventions</li> <li>• dietary restrictions</li> <li>• personality</li> </ul>	Review patient/family characteristics Review the status of active issues, compare with previous status measures Screen for any new issues or opportunities for growth Conduct a detailed history and examination of all new issues Assess for adverse events, medication interactions Assess adherence to plan of care and therapeutic protocols	Review the status of active issues Specify closure/transfer data

## Information-sharing

Communication is an essential part of the therapeutic relationship. It is always bidirectional. Figure #21 lists the different types of information shared during each phase of a therapeutic relationship.

**Figure #21: Variation in Information-sharing by Phase of Relationship**

Phase 1: Intake	Phase 2: Ongoing care	Phase 3: Closure (Discharge)
Establish patient/family's understanding of their illness/situation Establish limits of confidentiality Establish preferences patient has for "process to share information" Introduce the organization and the services it can offer Explain patient rights and responsibilities Share any pertinent information	Review understanding of illness/situation Review limits of confidentiality Review preferences for process to share information Share any pertinent information	Review understanding of illness/situation Share any pertinent information

When language is a barrier, formal caregivers have a responsibility to ensure the patient/family has access to effective translation to ensure clear communication and information sharing. Translation should be provided using people who understand both the concepts being conveyed, and the meaning of the words in both languages and cultures. If at all possible, clinicians should avoid using family members to translate, as they are often unskilled with medical terminology/concepts. In addition, asking a family member to translate may confuse her/his role as a family member with that of a healthcare provider.

## Decision-making

Figure #22 lists the different types of decision-making during each phase of a therapeutic relationship.

**Figure #22: Variation in Decision-making by Phase of Relationship**

Phase 1: Intake	Phase 2: Ongoing care	Phase 3: Closure (Discharge)
Assess capacity to make decisions Establish goals for care Prioritize issues Offer therapeutic options Facilitate choosing treatments Obtain consent Establish who surrogate decision-maker will be Establish advance directives Explain approach to conflict resolution Strive to resolve any conflicts	Assess capacity to make decisions Review goals of care Review issue prioritization Review treatment choices Offer any new therapeutic options Facilitate choosing treatments Obtain consent Strive to resolve any conflicts	Assess capacity to make decisions Review acceptability of closure/discharge

## Care Planning

Figure #23 lists the different types of care planning during each phase of a therapeutic relationship.

**Figure #23: Variation in Care Planning by Phase of Relationship**

Phase 1: Intake	Phase 2: Ongoing care	Phase 3: Closure (Discharge)
Choose setting of care Establish process to negotiate and develop plan of care Negotiate and develop the initial plan of care (IPOC)	Review appropriateness of setting of care Negotiate and develop, or review and update the continuous plan of care (CPOC)	Plan for transition Transfer plan of care to any ongoing healthcare providers (to ensure continuity)

## Care Delivery

Figure #24 lists the different approaches to care delivery during each phase of a therapeutic relationship.

**Figure #24: Variation in Care Delivery by Phase of Relationship**

Phase 1: Intake	Phase 2: Ongoing care	Phase 3: Closure (Discharge)
Establish initial careteam: <ul style="list-style-type: none"> <li>• engage formal and informal caregivers</li> <li>• establish who will lead, coordinate</li> <li>• provide initial education, support</li> <li>• initiate careteam communication tool</li> </ul> Request initial consultations Establish setting of care Establish which services will be essential Provide initial patient/family/extended network education/support Deliver initial therapies Establish safety, storage, handling, disposal strategies Establish infection control procedures Dispose of any medications, wastes Report any errors	Continue careteam development, education and support Follow up on any previous consultations Request new consultations Review setting of care Review essential services Provide ongoing patient/family/extended network education/support Deliver ongoing or new therapies Review safety, storage, handling, disposal strategies Review infection control procedures Dispose of any medications, wastes Review, report any errors	Adjourn and debrief careteam Close careteam communication tool Complete any consultations Provide final patient/family/extended network education/support Deliver final therapies Dispose of any medications, wastes Close safety, storage, handling, disposal strategies Report any errors

## Confirmation

Figure #25 lists the different approaches to confirmation during each phase of a therapeutic relationship.

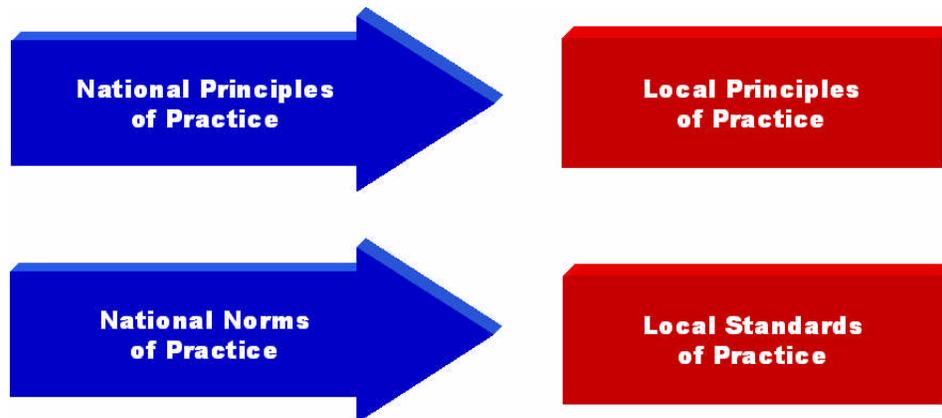
**Figure #25: Variation in Confirmation by Phase of Relationship**

<b>Phase 1: Intake</b>	<b>Phase 2: Ongoing care</b>	<b>Phase 3: Closure (Discharge)</b>
Establish understanding	Verify understanding	Verify understanding
Assess patient/family/caregiver satisfaction	Assess patient/family/caregiver satisfaction	Assess patient/family/caregiver satisfaction
Assess patient/family/caregiver perception of complexity, stress	Assess patient/family/caregiver perception of complexity, stress	Assess patient/family/caregiver perception of complexity, stress
Query for any concerns, other issues, questions	Query for any concerns, other issues, questions	Query for any concerns, other issues, questions

## Development of Principles and Standards of Practice

Clinicians and organizations can use the principles and norms of practice within the model to guide the development of local principles and standards of practice (see [section III on page 25](#) and [section IV on page 41](#)). The process of reviewing, modifying and accepting these concepts will be as important as the approach to care they adopt.

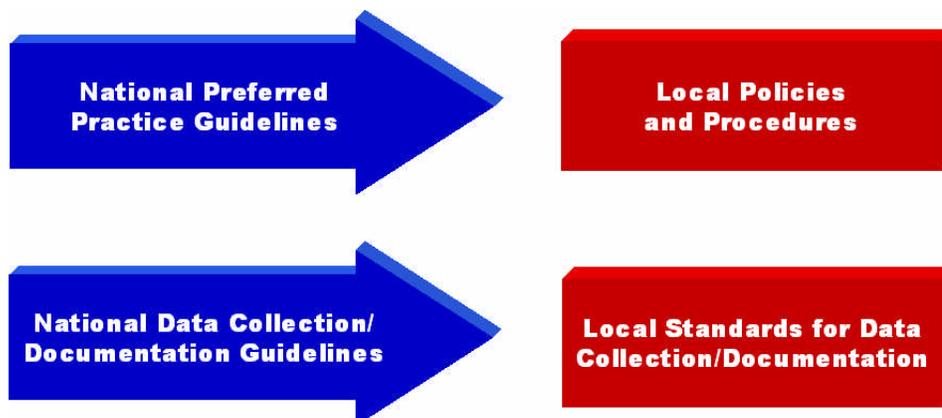
**Figure #26: Development of Principles and Standards of Practice**



## Development of Policies and Procedures, Standards for Data Collection/Documentation

Combined with preferred practice and data collection/documentation guidelines, clinicians can also use the model to guide the development of local policies and procedures, and standards for data collection/documentation for each issue commonly faced by patients and families (for an example, see [figure #29 on page 71](#)).

**Figure #27: Development of Policies and Procedures, Standards for Data Collection/Documentation**



## Other Clinical Applications

To be effective, clinicians must be appropriately educated and evaluated on an ongoing basis, and receive the support they need from colleagues and their organization. Through continuous application of the model, clinicians will develop a consistent approach to the process of providing care that:

- helps them develop reasonable expectations for prognosis and outcomes for each individual patient/family unit<sup>42,43</sup>
- minimizes the risk of errors<sup>44</sup>
- minimizes their occupational risk, overall sense of stress and the manifestations that come with it<sup>45</sup>
- reduces their risk of burnout/job turnover.

By combining the model for hospice palliative care with the funding and service delivery models in use in their jurisdiction, clinicians will be able to develop personal strategies for conducting therapeutic encounters, collecting clinically useful data, and documenting the patient/family issues and their therapeutic interventions in a manner that is consistent with widely-accepted practices, and minimizes the risk of reimbursement denials.

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## 2. Applying the Model to Organizational Development and Function

Hospice palliative care organizations develop in one of two ways: as independent entities or as part of a larger host organization. They are always subject to existing funding and service delivery models. Their success is dependent on all participants being:

- skilled at effective communication ([see page 21](#))
- skilled at group facilitation and dynamics ([see page 22](#))
- effective change agents ([see page 23](#)).

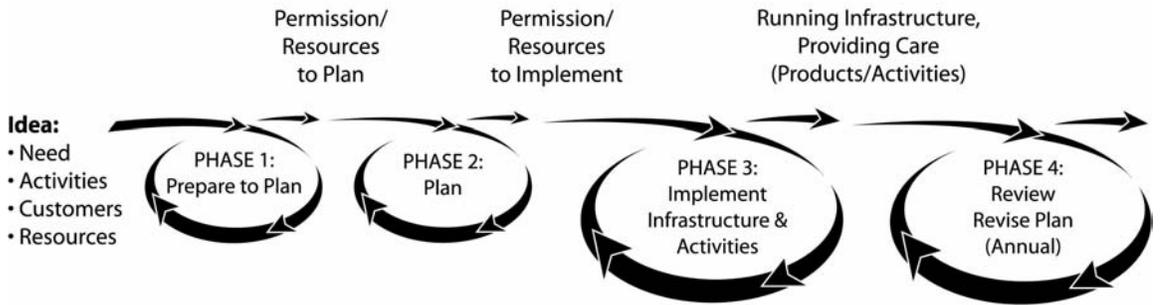
### Initial Idea

Administrators and clinicians who want to develop a hospice palliative care organization will start with an idea of:

- the need within their community
- their principal activities or product lines (e.g., clinical services, education of primary providers and/or hospice palliative care experts, research and/or advocacy)
- their customers (e.g., the referring primary healthcare providers, host organization, patients and families)
- the resources required to operate their principal activities and maintain their organizational infrastructure (e.g., financial, human, informational, physical and community resources, [see figure 13 on page 43](#)).

Once the organizers have their initial idea, they can embark on the 4 phase planning process shown in [figure #28 on the next page](#). The model outlined in this guide, and the *CAPC Manual: Everything You Wanted To Know About Establishing a Palliative Care Program But Were Afraid to Ask*, will both be useful resources to guide this developmental process.

**Figure #28: Planning Process for a Hospice Palliative Care Organization**



PHASE 1	PHASE 2	PHASE 3	PHASE 4
<ul style="list-style-type: none"> <li>Initiate initial workgroup</li> <li>Develop concept</li> <li>Develop planning proposal</li> <li>Seek permission and resources needed to plan</li> </ul>	<ul style="list-style-type: none"> <li>Identify planning workgroup, leaders, champions</li> <li>Conduct strategic planning</li> <li>Conduct business planning</li> <li>Develop proposal</li> <li>Seek permission and resources needed to implement the plan</li> </ul>	<ul style="list-style-type: none"> <li>Implement governance and administrative structure</li> <li>Implement infrastructure</li> <li>Acquire, develop, and manage resources</li> <li>Develop standards of practice, policies and procedures, standards for data collection and documentation</li> <li>Develop relationships with partner providers</li> <li>Develop safety, security, and emergency systems</li> <li>Implement the principal activities</li> <li>Implement the quality management and communications/marketing functions</li> </ul>	<ul style="list-style-type: none"> <li>Review outcomes, unmet needs, availability of additional resources</li> <li>Revise strategic and business plans for the following year</li> </ul>

## Phase 1: Prepare to Plan

During Phase 1, an organizing workgroup will develop their initial ideas into a planning proposal. This proposal will outline: the need, the concept for each of their principal activities, their customers and stakeholders, their planning process, and the resources required to complete the planning. The model to guide patient and family care ([see section III on page 25](#)) and organizational development and function ([see section IV on page 41](#)) can be used extensively to guide the development of these initial concepts.

Once the planning proposal is complete, the workgroup leaders and other champions will present the proposal to those who will provide resources and give permission for the full planning process (i.e., the administrators of the organization that will host the hospice palliative care organization, or the principal funders).

## Phase 2: Plan the Organization

Once the organizers have the permission and resources needed to proceed with planning, they can embark on a full strategic and business planning process to define the new organization. To start the process, they will form a planning workgroup and identify leaders and key individuals who will contribute to the planning process and/or champion the plan once it is complete.

### Strategic Planning

Strategic planning aims to define the organization, its product lines, and how it will be developed. Based on the concept developed in phase 1, the first steps in strategic planning will be to:

- identify key customers and stakeholders<sup>46</sup>
- conduct a needs assessment of the organization(s) who will host the new hospice palliative care organization and the community it will serve.<sup>47</sup>

This analysis will be used to justify the development of the new organization, guide its design, and identify other healthcare organizations that may become partners or competitors.

### Define The Organization

Once the needs assessment is complete, the workgroup can start to define the organization, its principal activities, clinical services, and developmental strategy. A number of concepts within the model can be used to guide the definition of the organization:

- The values and principles on which hospice palliative care is based can be used to develop the organization's values and principles ([see page 19](#)).
- The model mission and vision statements can be used to guide the development of the organization's mission and vision statements ([see page 42](#)).

### **Define Its Principal Activities**

Most new organizations will start by implementing a limited number of principal activities (e.g., a single clinical service that provides care in one setting, and education for a limited number of primary healthcare providers, [see page 41](#)). Once these have been implemented successfully, the range of activities can be expanded in subsequent years to meet the demonstrated need within the community.

### **Define Its Clinical Services**

Organizers can use the detailed list of domains and issues associated with illness and bereavement ([see figure #7 on page 15](#)) and the “Square of Care” ([see figure #11 on page 27](#)) to decide the issues to be addressed and the therapies to be provided by the organization’s clinical services, and those to be provided by partner organizations (i.e., to avoid any gaps in the care available to patients and families).

Organizers will also need to decide what types of care they will provide, in what settings, using which service delivery models.

### **Potential Types of Care**

Since the number of issues, their acuity, the duration of need, and the rapidity of the response required can vary considerably over the course of an illness and bereavement, planners must decide what types of care they will provide.

**Acute care.** At any time during the illness, from the outset to discharge, patients and families often experience a number of acute issues that require time-limited attention.

**Chronic care.** As the disease progresses, and the illness becomes life-threatening, patients and families may experience an increasing number of chronic issues that require continuous custodial or skilled nursing care.

**Respite care.** At times, family caregivers may become fatigued and require respite relief to give them a break or vacation.

**End-of-life care.** As the patient approaches the end of life, the acuity of issues and the need for care can rise considerably, particularly in the last hours of life when everything can change over a few hours to days.

**Bereavement care.** For those who survive the patient’s death, the intensity of need during bereavement typically waxes and wanes as the individuals realize what has happened, and recognize the significance of the loss to their lives. With time it slowly diminishes as they rebuild their lives and establish the new family group.<sup>48</sup>

**Response times.** Both standard and emergency response strategies will be needed for each of these types of care.

## Potential Service Delivery Models

To complete the definition of their clinical activities, organizers will need to choose service delivery models and the settings where they will provide care.

**Consultation / Primary Care Services:** Hospice palliative care organizations frequently develop an interdisciplinary team of experts that provides a mix of consultative and primary care services in one or more settings where patients and families receive care (see the side box on this page). Primary healthcare providers can then access the team for:

1. a one-time consultation with no ongoing follow-up
2. consultation with follow-up where the primary healthcare providers maintain overall responsibility for the patient's/family's care and the experts maintain a supporting role
3. consultation with follow-up where the experts assume overall responsibility and the original primary healthcare providers maintain a supporting role
4. consultation followed by assumption of the primary responsibility for the patient's/family's care (as the original primary providers stop being involved).

### Setting of Care

Patient/family care can be provided in a variety of settings, including:

- acute care facilities (e.g., general beds, intensive care units, emergency rooms in hospitals)
- long-term care facilities
- the patient's home (e.g., own home, boarding house, correctional facilities, on the street)
- office or clinic
- daycare centre
- free-standing hospice palliative care facility.

**Specialized Environments:** To facilitate access to more intensive hospice palliative care around the clock, many organizations develop specialized environments that provide expertise and skilled care 24-hours-a-day, seven-days-a-week, 365-days-a-year (24/7/365), and enhance the opportunity for family privacy and intimacy. While a specialized environment can be created "as needed" in the patient's environment, it is frequently more efficient for a hospice palliative care organization to have a number of beds it controls in one location, either within its own free-standing facility, or in a unit within an acute or long-term care facility.<sup>49</sup>

### Developmental Strategy

Finally, to complete strategic planning, the workgroup will need to establish goals and objectives, strategies and tactics, and the timelines and strategic decision points to develop the organization's infrastructure, and each of its principal activities.<sup>50</sup>

## Business Planning

Business planning describes the functions and resources required to deliver the organization's principal activities, and run its infrastructure. Once the strategic planning is well underway, the planning workgroup can use the "Square of Organization" and the associated principles and norms of practice to develop the organization's business plan<sup>51</sup> (see figure #14 on page 44, and pages 45-52).

Through business planning, the workgroup defines:

- the organization's governance and administrative structure, including leadership and accountability
- the plan to acquire and manage the needed financial, human, informational, physical and community resources (see figure #13 on page 43)
- the plan to implement and operate each of the principal activities, and the organization's infrastructure, including plans for the development of standards of practice, policies and procedures, and standards for data collection/ documentation (see pages 38 and 62)
- the quality management plan (see page 77)
- the communications/marketing plan (see page 86).

## Sell the Proposal

Once the strategic and business plans are complete, they are combined into a proposal and presented to those who will provide resources and give permission to build the new organization (i.e., the administrators of the organization that will host the hospice palliative care organization, or the principal funders). It requires careful planning to orchestrate the presentation and approval process to achieve a successful outcome.

## Phase 3: Implement and Run the Organization

Once the workgroup has the permission and resources needed to develop the organization, they can begin the process of implementing and running the new organization. They will need to:

- implement the governance and administrative structure, and select the leaders
- acquire, develop and manage all of the needed resources
- develop their standards of practice, policies and procedures, and standards for data collection and documentation
- develop their relationships with other partner providers to ensure that there is continuity of the plan of care, information and caregivers
- develop their safety, security and emergency systems
- implement each of the principal activities, and the quality management and communications/marketing functions
- ensure that all activities meet regulatory requirements for licensure/function.

A number of concepts within the model can be used to guide the operations of the organization. The process of reviewing, modifying and accepting these concepts will be as important as the approach to care adopted by the organization.

- The lexicon of commonly used terms can be used to develop definitions for the terms that will be used regularly within the organization (see appendices on page 91).
- The principles and norms of practice for patient and family care (see pages 28-37) can be used to guide the development of general and issue-specific standards of practice for each of the issues that will be addressed by the clinical services (see figure 29 on the next page).
- The principles and norms of practice for organizational function (see pages 46-52) can be used to guide the development of the general and resource-specific functions of the organization.
- Preferred practice guidelines (see page 38) can be used to guide the development of issue-specific policies and procedures.
- Data collection/documentation guidelines can be used to guide the development of issue-specific standards for data collection and documentation (see page 38 and 62).

Ultimately, organizers will need to develop tables that extend the “Square of Care” and detail the process of providing care for each issue commonly faced by patients and families. These tables will be similar to the tables in the 1995 Model<sup>52</sup> (for an example, see figure #29 on the next page). Similar tables will be developed to extend the “Square of Organization” and detail the principal functions to acquire and manage the resources required to maintain the organization’s infrastructure and run its activities.

**Figure #29: Sample Table of Standards of Practice, Policies and Procedures, Standards for Data Collection and Documentation for a Specific Issue**

	<b>Standards of Practice</b>	<b>Policies and Procedures</b>	<b>Standards for Data Collection and Documentation</b>
<b>Assessment</b>	Standards of practice for assessment related to the issue	Policies and procedures to guide assessment of the issue	Status and context of the patient and family related to the issue Related expectations, needs, hopes, fears Etiologies Perceived benefits, burdens from previous therapies Adverse events
<b>Information sharing</b>	Standards of practice for information sharing related to the issue	Policies and procedures to guide information sharing related to the issue	Information discussed related to the issue Emotional reactions Understanding of the information shared related to the issue
<b>Decision-making</b>	Standards of practice for decision-making related to the issue	Policies and procedures to guide decision-making related to the issue	Goals of care related to the issue Priority of the issue Therapeutic options offered with their potential for benefit, risk, burden Treatment(s) chosen Advance directives related to the issue
<b>Care Planning</b>	Standards of practice for care planning related to the issue	Policies and procedures to guide care planning related to the issue	Setting of care Plan to deliver care related to the issue
<b>Care Delivery</b>	Standards of practice for care delivery related to the issue	Policies and procedures to guide care delivery related to the issue	Careteam activities, training and support related to the issue Consultation related to the issue Patient/family/extended network education and support related to the issue Therapies given, with any effects experienced (benefits, adverse events) Errors related to the issue
<b>Confirmation</b>	Standards of practice for confirmation related to the issue	Policies and procedures to guide confirmation related to the issue	Understanding related to the issue Satisfaction related to the issue Perception of complexity and stress related to the issue Ability to provide and participate in the plan of care

**Note:** Examples of the standards for data collection and documentation have been included to illustrate the potential breadth of the data that might be collected for each issue. Specific guidelines will be needed for each issue to ensure usefulness and practicality.

## Phase 4: Review the Organization Annually and Revise the Plan

At the end of each year, as part of its quality management activities, each organization will review:

- the outcomes of its principal activities and infrastructure
- the unmet needs within its host organization(s) and the community it serves
- the availability of additional resources.

Based on this analysis, each organization will repeat a variation of planning phases two to four and revise its strategic and business plans, standards of practice, policies and procedures, and standards for data collection/documentation for the coming year.

### Organizational Labeling

Depending on their size and relationships, hospice palliative care organizations choose a variety of different labels or names for themselves. Some will call themselves ‘services’; others will call themselves ‘programs’.

**Services** tend to be part of a larger organization (e.g., a host organization or a program). They have one or more component activities. Most will not have their own governance structure.

**Programs** may be part of a larger host organization, or independent. They are usually involved in more than one component activity or service, and may or may not have their own governance structure.

In some jurisdictions, the label that an organization uses will be based on minimum or licensure standards. Depending on whether these standards were developed by an association or a regulatory body, compliance and the use of a given label may be voluntary or mandatory.

In its 1989 Palliative Care Services Guidelines, Health and Welfare Canada suggested a functional classification for palliative care programs.<sup>53</sup> From the outset, it was clear that one or two well-intended caregivers who provide a few aspects of hospice palliative care can only be considered to be a preliminary service. Today, a variation of this classification might still apply:

**Level 0 – Preliminary Service:** a service that provides only a few hospice palliative care services. Typically there are one or two experts, but not a full interdisciplinary team.

**Level I – Core Clinical Program:** a service or program that provides the full range of clinical services needed to address the issues commonly faced by patients and families throughout the illness and bereavement experiences. Care is provided by an interdisciplinary team that includes one or more clinically-active expert physicians, nurses, social workers/psychologists, chaplains, pharmacists and volunteers. Program functions include quality management and communications/marketing.

**Level II – Complete Program:** a service or program that integrates a full range of clinical services to provide care throughout the illness and bereavement experiences, education for primary healthcare providers, research and advocacy. Each of these activities are provided by an interdisciplinary team that includes one or more expert physicians, nurses, social workers/psychologists, chaplains, pharmacists and volunteers. Program functions include quality management and communications/marketing.

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### 3. Applying the Model to Careteam and Regional Team Development and Function

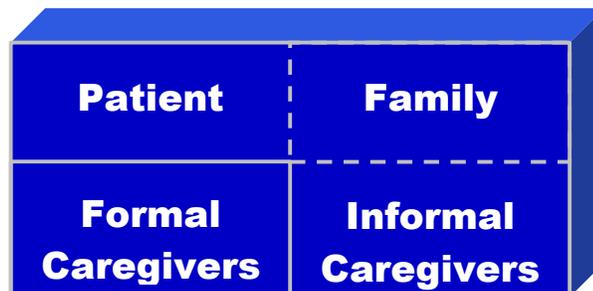
Careteams and regional teams are in essence “mini” organizations. Careteams take on the task of caring for an individual patient and family unit, in order to change their experience of illness and bereavement. Regional teams are functional units within hospice palliative care organizations designed to provide formal caregivers an oversight to multiple patient/family careteams within a given population/region/setting of care. To operate effectively, each team needs all of the same types of resources, functions and infrastructure as any larger organization.

As the following careteam example illustrates, all aspects of the model to guide organizational development and function can be applied to both careteam and regional team formation and function (see section IV on page 41).

#### Careteam Development and Function

As noted in section II of this guide, hospice palliative care is most effectively provided by interdisciplinary careteams, which form around individual patient/family units to provide care.

**Figure #30: Patient / Family Careteam**



Development of an effective careteam is dependent on the formal caregivers being:

- skilled at effective communication (see page 21)
- skilled at leading and facilitating careteam formation and function (see page 22)
- effective change agents (see page 23).

As with any other organization, a careteam develops through four phases (see figure #31 on page 76). However, because a careteam is a time-limited organization developed to meet the needs of a patient/family, it goes through one additional phase in its life cycle when its services are no longer required: adjournment.

## Phase 1: Prepare to Plan

From the outset, an individual patient and family may need care for any number of issues ([see figure #7 on page 15](#)). The formal caregiver who assesses their needs on intake, discusses the potential for an interdisciplinary careteam with them as part of care planning, and seeks their permission to proceed.

## Phase 2: Plan

Once permission is received, the formal caregiver will develop the plan for the careteam and its activities.

Strategic planning for any careteam is relatively straightforward. The customers are the patient and family. The stakeholders are the formal and informal caregivers, the patient's and family's extended network, the hospice palliative care organization, and any other healthcare or community organizations involved in their care. The needs assessment is conducted as part of the intake assessment and the ongoing process of providing care. The careteam's values and principles are based on those for hospice palliative care ([see page 19](#)). Its mission is to care for the patient and family, and its vision is developed from the patient's and family's goals for care. Its principal activity is to provide the type of care required in the care setting chosen during care planning.

Business planning is much more specific to individual patient and family situations, and can be guided by the "Square of Organization" ([see page 45](#)). Each careteam will be led by a designated formal caregiver who is skilled at careteam formation, understands how to manage careteam dynamics, and knows how to coordinate the process of providing care. An informal caregiver and/or the patient may assist with leadership.

Each careteam leader will plan for:

- the financial, human, informational, physical and community resources to support the careteams activities
- the formation, education, implementation, management and support of the careteam and its activities
- routine review of the careteam activities
- a communications strategy among careteam members.

### Phase 3: Implement the Plan

When the plan of care is in place and the resources are available, the careteam leader(s) will implement the plan of care. Infrastructure and administrative support typically come from the hospice palliative care organization.

**Resource acquisition and management:** Most careteams use a mix of resources that come from the patient and family, the hospice palliative care organization, other parts of the healthcare system, and the community. Acquisition, development and management of each of these resources will take a considerable amount of the leaders' time. There will need to be:

- **Financial resources:** Sufficient financial resources to support the careteam's activities and the delivery of care.
- **Human resources:** Enough caregivers who are competent and confident to deliver the needed care.

**Careteam formation:** Wherever possible, careteams include a mix of formal and informal caregivers. Formal caregivers are chosen from the hospice palliative care organization's regional team for their skills required to deliver the plan of care. Most careteams will include one or more primary and/or expert physicians, nurses, social workers, chaplains, pharmacists and caregiving volunteers. Informal caregivers are typically family members and friends who wish to be involved. Other disciplines and consultants will join the team as needed. Careteam leaders must be careful to give everyone a role, but be selective in ensuring that those who provide direct patient care are both capable and properly motivated. It is also important to ensure family members are not distressed by their caregiving roles and have time to maintain their "family" roles.

**Careteam education:** Formal caregivers receive ongoing education and evaluation through the hospice palliative care organization. Informal caregivers must be taught the specific skills they need to do the tasks assigned to them.

**Careteam support:** Caregivers require ongoing self-care. Leaders must ensure team members have resources and opportunities to share their experiences/feelings.

- **Informational resources:** A data collection/documentation tool that provides a health record for the patient and a communication tool for the careteam; a schedule to manage the caregivers' hours and activities; and resource materials to supplement caregiver education and training.
- **Physical resources:** Medical equipment, medications and supplies to provide care.
- **Community resources:** Community resources to supplement the careteam's resources and activities.

**Operations:** When the caregivers and the resources are in place, the careteam will begin to provide care to the patient and family. All careteam activities will be guided by the hospice palliative care organization's standards of practice, policies and procedures, and standards for data collection and documentation.

**Communications:** To support the careteam's activities, an effective communication strategy will need to be developed and maintained by the leaders and the hospice palliative care organization.

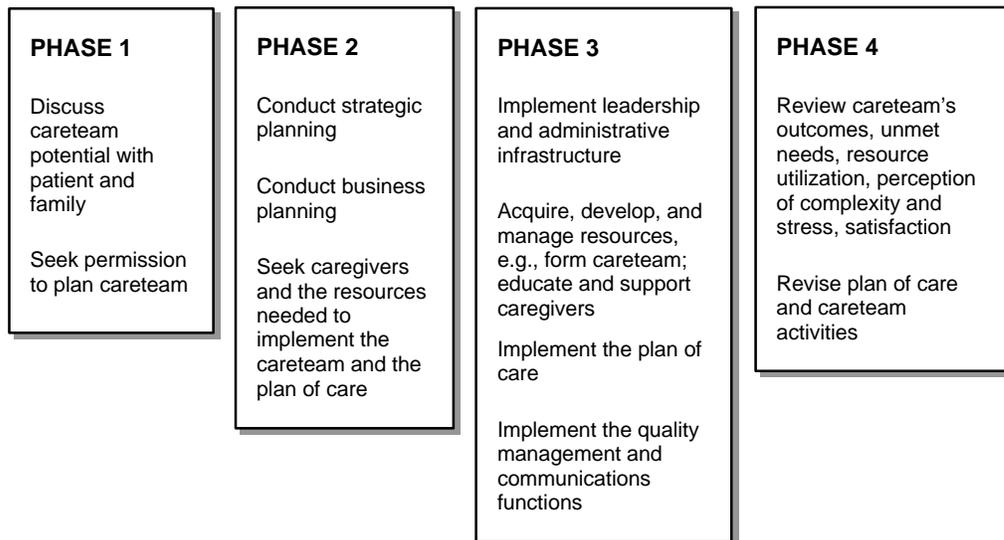
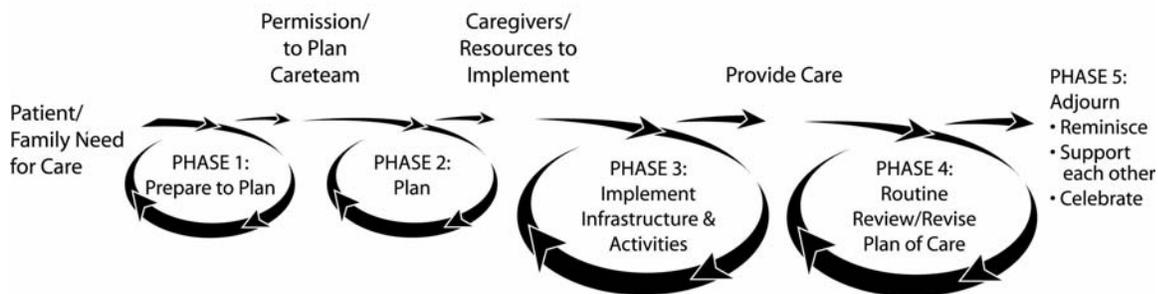
## Phase 4: Review and Revise the Plan (Quality Management)

At regular intervals — usually once a week — formal caregivers and other key members of the hospice palliative care organization will review each careteam’s activities to assess them for overall outcomes, unmet needs, resource utilization, perception of complexity and stress, and caregiver satisfaction. Changes are made to the plan of care and the careteam’s activities as required.

## Phase 5: Adjourn

When the patient and family no longer need the careteam, it must adjourn. To bring closure to the therapeutic relationship and the group’s activities, it is important that the careteam meet as a whole one last time to reminisce, support each other, and celebrate their accomplishments. If the patient has died in the process, careteams will often integrate a memorial service to commemorate the person they have cared for.

**Figure #31: The Life Cycle of a Careteam**



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## 4. Applying the Model to Quality Management

One of the goals of a national model is to provide an effective means to compare activities both within and between organizations. As all hospice palliative care activities aim to change the experience of illness and bereavement, assessing their effectiveness at meeting this goal must be an integral part of each organization's principal functions.

**Quality managers** can use this model to guide the development of a comprehensive quality management strategy to review both patient and family care, and organizational development and function.

### Standards of Practice, Policies and Procedures, Standards for Data Collection/Documentation

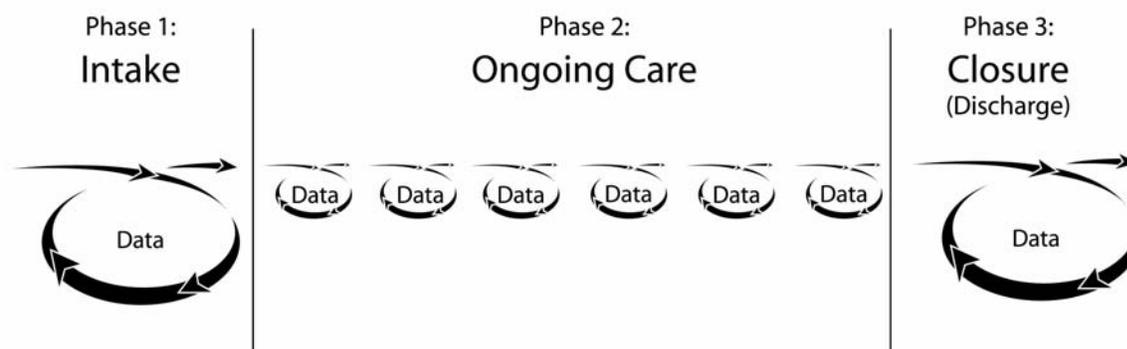
The model to guide hospice palliative care presents a conceptual framework, the "Square of Care", and principles and norms of practice for all aspects of patient and family care, and a conceptual framework, the "Square of Organization", and principles and norms of practice for all aspects of organizational development and function. When combined with preferred practice guidelines and data collection/documentation guidelines, the model can be used to guide the development of general and issue-specific standards of practice, policies and procedures, and standards for data collection and documentation in each hospice palliative care organization ([see pages 38 and 62](#)).

### Outcome Assessment

During each therapeutic encounter, clinicians will collect the data required to document the status of each issue the patient and family face, and any action taken during the encounter. By comparing the status, perceived complexity and stress, and satisfaction data from successive therapeutic encounters, quality managers will be able to assess a variety of different outcomes and trends related to the organization's clinical activities ([see figure #32 on the next page](#)).

By collecting resource utilization and adverse events data, quality managers will be able to assess a variety of different outcomes and trends related to the organization's function.

**Figure #32: Comparison of Data from Successive Therapeutic Encounters**



**Simple outcome comparisons** can be made by comparing single data fields from successive encounters (e.g., the change in severity of the patient’s pain from one encounter to the next; or the caseload of the organization on a given day).

**Complex outcome measures (or indicators)** can be calculated from multiple data fields collected over several therapeutic encounters (e.g., the percent of patients whose pain was <5/10 on a visual analogue scale 48 hours after admission; or the average length of stay of patients with a cancer diagnosis who died while in the program).<sup>54</sup>

Using the data and simple analytic techniques, quality managers will be able to assess the outcomes of care and program function from many different perspectives:

- each patient and family unit
- each careteam
- each regional team in the organization
- the organization
- the population served by the organization
- the population within a given region (i.e., population data surveillance)
- special interest groups.

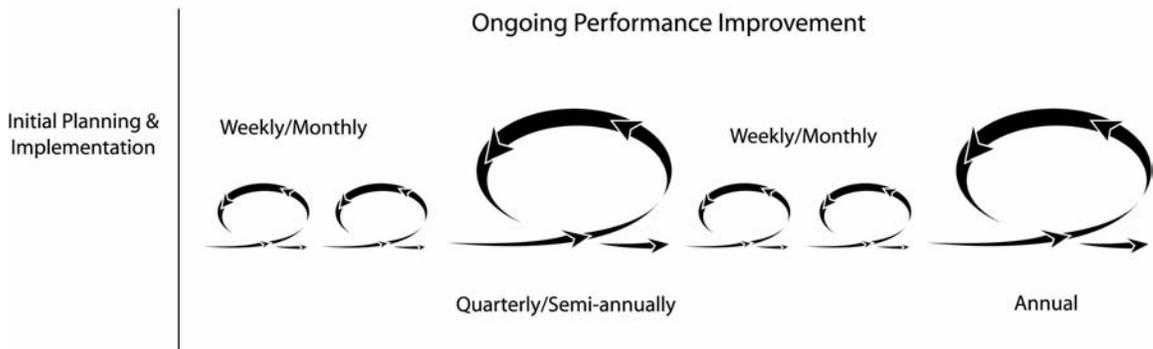
## Performance Improvement

Once an organization is fully functional, the quality review cycles will vary depending on the perspective and the issue under consideration (see figure #33 on the next page). For example:

**Short cycle performance improvement strategies** will review data on a daily, weekly or monthly basis with a view to making rapid improvements (e.g., Institute for Healthcare Improvement’s Plan-Do-Study-Act strategy for accelerating improvement<sup>55</sup>).

**Long cycle performance improvement strategies** will review data on a quarterly, semi-annual, or annual basis (or longer) with a view to making long-term improvements (e.g., the phase 4 review of an organization discussed earlier in this section).

**Figure #33: Quality Review Cycles**



**Figure #34: Review Frequency for Different Strategies**

Perspective	Review Frequency
Clinical outcomes (status, actions, perception of complexity/stress, satisfaction)	
Individual patients and families	Day to day
Careteams	Weekly
Regional teams	Weekly, monthly, annually
Overall program	Monthly, annually
Population served	Annually
Resource utilization	Monthly, quarterly, annually
Adverse events/risk management	Monthly, quarterly, annually
Compliance	Monthly, quarterly, annually
Strategic and business plans	Annually
Standards of practice	Annually
Policies and procedures	Annually
Standards for data collection	Annually

To see how well the organization is functioning, comparisons can be made with:

- historical data
- the organization’s standards of practice
- the nationally-accepted norms of practice within this model.

## Accreditation

**Accreditors** will find the model provides frameworks, principles and norms of practice to guide the development of accreditation standards that can be used to assess both patient/family care and organizational function.<sup>56,57,58,59</sup> Although the model is specifically designed for hospice palliative care organizations, the accreditation standards and target outcomes should be the same for similar activities in any healthcare organization.

In addition to inter-organizational comparisons (benchmarking), the model's norms of practice can be used during an external review as another point of comparison (i.e., "the ideal to which organizations can aspire").

## Standards of Professional Conduct

As all healthcare providers should be able to provide the core competencies of hospice palliative care, aspects of the model can be used to guide the development of standards of professional conduct by professional associations and licensing bodies.

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## 5. Applying the Model to Education

As all patients and families will experience issues within the domains of hospice palliative care, all healthcare providers must be competent at providing at least the core skills of hospice palliative care. To change patients' and families' experience of illness and bereavement, clinicians (including volunteers) must:

- have the attitudes and knowledge necessary to address hospice palliative care issues
- be skilled at the process of providing care related to each of these issues
- change their own behaviour as they manage these issues.<sup>60,61</sup>

**Healthcare educators** will be able to adapt the “Square of Care” and the principles and norms of practice for patient and family care to guide the development of core competencies, curricula (i.e. The Canadian Palliative Care Curriculum<sup>62</sup>), and examination strategies for both primary and expert hospice palliative care providers from all disciplines (including volunteers). Educators will also be able to adapt the “Square of Organization” and the principles and norms of practice for organizational development and function to guide the development of educational strategies for administrators and quality managers.

The model will be particularly useful to guide:

- The development of educational standards for hospice palliative care experts:

### **Nurses**

- CHPCA Hospice Palliative Care Nursing Standards of Practice, 2002,<sup>63</sup> developed in collaboration with the Canadian Nurses Association<sup>64</sup>
- Nursing certification through the National Board for Certification of Hospice and Palliative Nurses in the U.S.<sup>65</sup>

### **Physicians**

- Standards of Accreditation for a 1-year Program of Added Competence in Palliative Medicine, The Royal College of Physicians and Surgeons of Canada<sup>66</sup> and the College of Family Physicians of Canada<sup>67</sup>
- Initial voluntary program standards for fellowship training in palliative medicine in the U.S.,<sup>68</sup> supported by the American Board of Hospice and Palliative Medicine<sup>69</sup>

### **Social Workers**

- [Competency-based Education for Social Workers](#). Alexandria, VA: National Hospice and Palliative Care Organization, 2001.
- **Medical schools in Canada and the U.S.** that are now required to teach end-of-life care. According to the Liaison Committee on Medical Education in the U.S.: “Clinical instruction should cover all organ systems, and must include the important aspects of preventive, acute, chronic, continuing, rehabilitative, and end-of-life care.”<sup>70</sup> This also applies to Canadian medical schools: “The Committee on the Accreditation of Canadian Medical Schools (CACMS) serves as a mechanism to ensure high standards on a national basis, as well as meeting accreditation standards of our U.S. counterparts, the Liaison Committee for Medical Education (LCME).”<sup>71</sup>

- **Residency training programs in the U.S.** that are now required to teach pain management and end-of-life care, e.g., family medicine,<sup>72</sup> internal medicine.<sup>73</sup> For example, the special educational requirements for general internal medicine and internal medicine subspecialty training include:

“Pain management: Each resident should receive instruction in the principles and practice of pain management, including symptom assessment and control.”<sup>73</sup>

“End-of-life care: Each resident should receive instruction in the principles of palliative care for terminally ill patients, including the role of the health-care team. Instruction should include psychosocial, cultural, and religious issues related to death and dying. It is desirable that residents participate in hospice and home care.”<sup>73</sup>
- **Continuing medical education programs** specializing in end-of-life care, hospice care, pain management and palliative care, including:

The Ian Anderson Continuing Education Program in End-of-Life Care<sup>74</sup>

The Pallium Project<sup>75</sup>

The Education for Physicians on End-of-life Care (EPEC) Project<sup>76</sup>

The End-of-Life Nursing Education Consortium (ELNEC) Project<sup>77</sup>

The End of Life Physician Education Resource Center<sup>78</sup>

Provincial/state regulations mandating education in end-of-life care, such as California Bill AB 487 mandating 12 hours of physician education in pain management and the treatment of terminally ill and dying patients by December 31, 2006.<sup>79</sup>

**Hospice palliative care organizations** proposing to develop “education” as one of their principal activities, will also find that the “Square of Organization” and the principles and norms of practice for organizational development and function can be used to guide the development of their educational activities. To date, specific norms of practice have not been developed to guide educational activities.

**Note:** Education of patients, families, and informal caregivers is part of care delivery (see page 34). Education of staff (e.g., formal caregivers) is part of the development of human resources (see page 43).

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## 6. Applying the Model to Policy Development

An initial review of the impact of the 1995 Principles of Practice<sup>80</sup> demonstrated that even the first working document on national standards of practice can change approaches to care within organizations and across healthcare regions, as well as provincial and federal policy.<sup>81</sup>

**Regulators, policy makers and funders** will be able to use the new model's conceptual frameworks, the "Square of Care" and the "Square of Organization", to guide the review and improvement of existing laws, regulations and policies. Each law, regulation and policy will fit somewhere on the grids created by these frameworks. Queries might include:

- What existing laws, regulations and policies guide hospice palliative care practice and program development?
- Do they create any barriers to providing patient/family care or developing effective hospice palliative care organizations?
- Are there aspects of patient/family care and organization function that would benefit from new policy, regulation, or law?

The "Square of Care" and the "Square of Organization" will also be used to guide the review and improvement of existing funding and service delivery models. Queries might include:

- What resources are currently available to fund hospice palliative care activities?
- What activities do they facilitate?
- Are there gaps in the funding or service delivery models that create barriers to good patient/family care?
- How should funding and/or service delivery models be changed to overcome those gaps?

As an example of the potential impact of review: when California realized that private healthcare insurers were not providing hospice care consistent with the U.S. Medicare Hospice Benefit, they created legislation that made it mandatory for "each health care service plan [to] include as a basic health care service, hospice care that at a minimum shall be equivalent to that provided pursuant to the federal Medicare program".<sup>82</sup>

### Population Data Surveillance Strategies

To understand how populations of patients receive hospice palliative care, policy makers will be able to use the norms of practice within the model to help develop national data collection and documentation guidelines. Once in widespread use, consistent data collection strategies will help policy makers and regulators develop population data surveillance strategies.

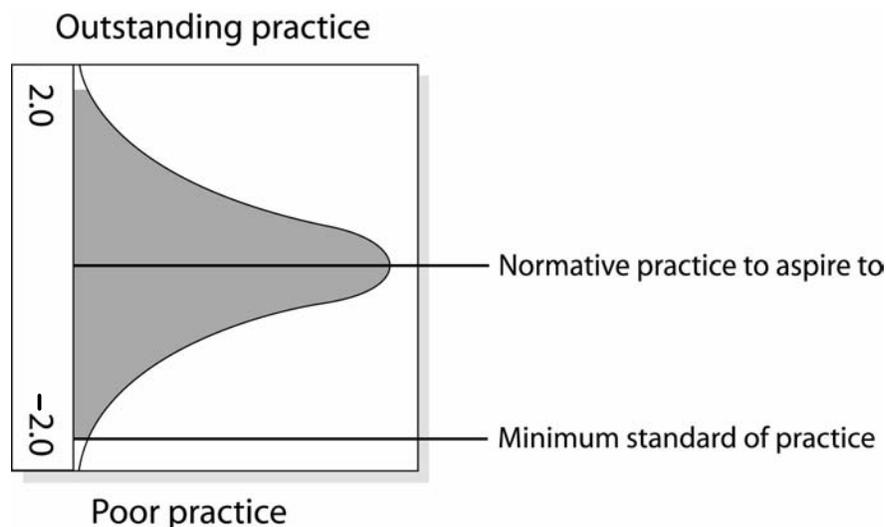
## New Policy, Regulation, Law, Funding or Service Delivery Models

Policy makers will also be able to use the model to guide the development of new policy, regulation, and law, funding or service delivery models (e.g., provincial/state hospice palliative care policy and funding/service delivery strategies.) Their content should be consistent with the model's principles and norms of practice, and encourage the widespread implementation of high quality hospice palliative care.

## Minimum/Licensure Standards of Practice

Minimum standards of practice are frequently developed by stakeholder associations to guide their members' practice, or by policy makers who wish to regulate an industry (e.g., the Conditions of Participation of the U.S. Medicare Hospice Benefit).<sup>83</sup> Minimum standards are different from norms of practice. They establish the "floor" or "minimum practice" that is acceptable to meet a given condition (i.e., labeling, licensure).

**Figure #35: Minimum Standards of Practice**



Compliance with "minimum standards" may be:

- voluntary if the "minimum" performance criterion is established as a guide (e.g., guidelines to define the labeling of hospice palliative care programs, such as the functional classification of a palliative care program presented in the 1989 Palliative Care Services Guidelines)<sup>84</sup>
- mandatory if the "minimum" performance criterion is legislated or regulated, and labeling or licensure can be revoked if the conditions are not met (e.g., the Conditions of Participation of the U.S. Medicare Hospice Benefit ).<sup>41</sup>

The model presented in this monograph might be used to guide the development of minimum/licensure standards. However, policy makers are reminded that the principles and norms of practice within the model present the ideal practice to which hospice palliative care providers and organizations can aspire. They do not represent current standards of practice.

While minimum or labeling standards may contribute to the development of hospice palliative care, policy makers are cautioned not to create licensure standards prematurely without data to support their usefulness, and careful analysis of the potential for secondary unintended consequences.

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## 7. Applying the Model to Research

**Researchers** will be able to use the model to identify new research initiatives to advance both the delivery and organization of hospice palliative care. The grids of both the “Square of Care” and the “Square of Organization” can be used to map out the existing literature, identify gaps in knowledge, and suggest research priorities.

**Administrators, clinicians and educators** will be able to use this same review process to identify existing knowledge and skills that are not well integrated into clinical practice or organizational function. They can then develop strategies to disseminate the information to end-users and integrate it into routine practice.

Hospice palliative care organizations proposing to develop “research” as one of their principal activities, will also find that the “Square of Organization” and the principles and norms of practice for organizational development and function can be used to develop their research activities. To date, specific norms of practice have not been developed for research activities.

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## 8. Applying the Model to Advocacy and Communications/ Marketing

### Advocacy

A concerted advocacy effort by many organizations using the nationally-accepted model has the potential to have a significant impact and be a force for change. For example, the model could be used to:

- trigger the development of community associations and partnerships of hospice palliative care organizations and providers to deliver care and advocate for change
- guide advocacy aimed at changing organizational, regional, and national policy, and funding/service delivery models
- enhance consumer and provider awareness of all aspects of hospice palliative care.

The definition, values and guiding principles in section II ([see pages 17-20](#)) will help shift the understanding of hospice palliative care. Instead of being seen as “care for the dying”, hospice palliative care will be “care that aims to relieve suffering and improve quality of life throughout the illness experience and bereavement, so that patients and families can realize their full potential to live even when they are dying”.

The “Square of Care,” principles and norms of practice will help to change consumers’ expectations of their healthcare providers (i.e., the issues they can expect to have addressed, the process of providing care they can ask for, the approach to careteam function they can anticipate, when to access hospice palliative care services). Overall, it will enhance consumers’ confidence and encourage them to ask questions of their healthcare providers.

Hospice palliative care organizations proposing to develop “advocacy” as one of their principal activities, will also find that the “Square of Organization” and the principles and norms of practice for organizational development and function will help to develop their advocacy activities. To date, specific norms of practice have not been developed to guide advocacy activities.

### Communications/Marketing

The model will serve as a cornerstone to guide communications and marketing. Having a nationally accepted model will make it easier to develop consistent messages that everyone can support (e.g., *Living Lessons*, an innovative social marketing campaign that was based on the 1995 Principles of Practice).<sup>85</sup>

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## Conclusion

The success of modern medicine has markedly changed the experience of illness and bereavement. Today, people are living for much longer with the multiple issues that are the manifestations, predicaments and opportunities presented by their underlying disease, conditions, or aging. In the process, they experience prolonged suffering, and considerable change to the quality of their lives. It affects not only the patient, but also their families, and the communities in which they live.

This monograph defines hospice palliative care and presents a model that includes conceptual frameworks, principles and norms of practice to guide all aspects of patient/family care, and organizational development and function. It is hoped that, through application of the model, all healthcare providers will become more effective at relieving suffering and improving quality of life. It is also hoped that, with time, there will be widespread application of hospice palliative care throughout the experience of illness and bereavement, “so that patients and families can realize their full potential to live even when they are dying”.

In the end, our society’s ability to realize its potential will be related to its success at relieving suffering. The health and compassion of our communities will be related to the degree of integration of hospice palliative care into all aspects of our healthcare system. For our patients, our families, our communities, and ultimately ourselves, isn’t it time to get going?

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URLs were last updated March 23, 2002.

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- <sup>40</sup> Emanuel LL, Alpert HR, Emanuel EE. Concise Screening Questions for Clinical Assessments of Terminal Care: The Needs Near the End-of-Life Care Screening Tool. *Journal of Palliative Medicine*, 2001; 4(4): 465-474.
- <sup>41</sup> Conditions of Participation, Medicare Hospice Benefit, Code of Federal Regulations, Title 42, Chapter IV, Part 418.
- <sup>42</sup> Christakis NA. *Death Foretold: Prophecy and Prognosis in Medical Care*. Chicago, IL: University of Chicago Press, 1999.
- <sup>43</sup> *Medical Guidelines For Determining Prognosis In Selected Non-Cancer Diseases – Second Edition*. Alexandria, VA: National Hospice and Palliative Care Organization, 1996. See item #713008.
- <sup>44</sup> Committee on Quality of Health Care in America, Institute of Medicine, Kohn LT, Corrigan JM, Donaldson MS (eds). *To Err is Human: Building a Safer Health System*. Washington, DC: National Academy Press, 2000.
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- <sup>46</sup> von Gunten CF, Ferris FD, Portenoy RK, Glajchen M. Review Stakeholders and Customers, in CAPCManual: How to Establish a Palliative Care Program. New York, NY: Center to Advance Palliative Care, 2001.
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- <sup>53</sup> Working Group on Palliative-Care Services, Subcommittee on Institutional Program Guidelines. *Palliative-Care Services Guidelines*. Ottawa, ON: Health and Welfare Canada, 1989.
- <sup>54</sup> *A Guide to the Development and Use of Performance Indicators*. Ottawa, ON: Canadian Council on Health Services Accreditation, 1996.
- <sup>55</sup> [Institute for Healthcare Improvement End of Life Resources](#).
- <sup>56</sup> [Canadian Council on Health Services Accreditation](#).

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- <sup>57</sup> Joint Commission on Accreditation of Healthcare Organizations.
- <sup>58</sup> National Committee for Quality Assurance.
- <sup>59</sup> Picker Institute Europe.
- <sup>60</sup> Dixon J. Evaluation criteria in studies of continuing education in the health professions: a critical review and a suggested strategy. *Eval Health Prof* 1978 Summer; 1(2): 47-65.
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- <sup>62</sup> Macdonald N. *The Canadian Palliative Care Curriculum*, 1991.
- <sup>63</sup> CHPCA Nursing Standards Committee. *Hospice Palliative Care Nursing Standards of Practice*. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.
- <sup>64</sup> Canadian Nurses Association, Ottawa, Ontario, Canada.
- <sup>65</sup> National Board for Certification of Hospice and Palliative Nurses.
- <sup>66</sup> Standards of Accreditation for a 1-year Program of Added Competence in Palliative Medicine, The Royal College of Physicians and Surgeons of Canada, Approved April 1999.
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- <sup>68</sup> Billings JA, Block SD, Finn JW, LeGrand SB, Lupu D, Munger B, Schonwetter RS, von Gunten CF. Initial voluntary program standards for fellowship training in palliative medicine. *J Palliat Med* 2002 Feb; 5(1): 23-33.
- <sup>69</sup> Proposed Palliative Medicine Fellowship Standards, American Board of Hospice and Palliative Medicine.
- <sup>70</sup> Accreditation Standards, Liaison Committee on Medical Education, July 2000.
- <sup>71</sup> Committee on the Accreditation of Medical Schools.
- <sup>72</sup> Recommended Curriculum Guidelines for Family Practice Residents, End-of-Life Care. American Academy of Family Practice.
- <sup>73</sup> Program Requirements for Residency Education in Internal Medicine, Accreditation Council for Graduate Medical Education, effective July 2001.
- <sup>74</sup> The Ian Anderson Continuing Education Program in End-of-Life Care.
- <sup>75</sup> The Pallium Project.
- <sup>76</sup> The Education for Physicians on End-of-life Care (EPEC) Project.
- <sup>77</sup> The End of Life Nursing Education Consortium (ELNEC) Project.
- <sup>78</sup> The End of Life Physician Education Resource Center.
- <sup>79</sup> Bill AB 487, State of California, October 4, 2001.
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- <sup>81</sup> Meredith Associates, Preliminary Impact Analysis of the National Consensus Standards for Palliative Care, Prepared for the Canadian Hospice Palliative Care Association, March 2000.
- <sup>82</sup> Assembly Bill AB 892, State of California, September 27, 1999.

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<sup>83</sup> Conditions of Participation, Medicare Hospice Benefit, Code of Federal Regulations, Title 42, Chapter IV, Part 418.

<sup>84</sup> Subcommittee on Institutional Program Guidelines. Palliative-Care Services Guidelines. Ottawa, ON: Health and Welfare Canada, 1989, 5.

<sup>85</sup> Living Lessons, developed by the GlaxoSmithKline Foundation.

# Appendices

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## Lexicon of Commonly Used Terms

<b>Activities of daily living</b>	Daily personal care activities, including ambulation, bathing, toileting, feeding, dressing and transfers. May also include cooking, cleaning, laundry, banking, shopping.
<b>Advance directives</b>	A patient's formal or informal instructions concerning expectations of care and choice of treatment options in response to potential illnesses or conditions (legal connotations vary by jurisdiction; includes a living will).
<b>Accountability</b>	The fiduciary and professional responsibility to those receiving care and the community.
<b>Alternate, complementary, integrative therapies</b>	Terms often used to describe independent healing systems outside the realm of conventional medical theory and practice.
<b>Assess</b>	To identify, describe, evaluate and validate information.
<b>Autonomy</b>	The state of being self-governed.
<b>Beneficence</b>	The provision of benefits and the balancing of harms and benefits for the purpose of doing the most good.
<b>Bereavement</b>	The state of having suffered the death of someone significant.
<b>Care</b>	All interventions, treatments and assistance to the patient and family.
<b>Care plan</b>	<a href="#">See "Plan of Care" on page 94.</a>

**Caregiver** Anyone who provides care.

**Formal caregivers** are members of an organization and accountable to defined norms of conduct and practice. They may be professionals, support workers, or volunteers. They are sometimes called “providers.”

**Informal caregivers** are not members of an organization. They have no formal training, and are not accountable to standards of conduct or practice. They may be family members or friends.

**Confidentiality** The protection and control of information privy to persons.

**Discrimination / prejudice** Any act by another that inhibits a person’s ability to fully participate in society, especially when related to age, gender, national and ethnic origin, geographical location, race, colour, language, creed, religion, sexual orientation, diagnosis, disability, availability of a primary caregiver, ability to pay, criminal conviction, family status.

**Essential services** The critical services required to implement the plan of care.

**Essential step** Any activity that is required to meet a stated objective.

**Expectations** Issues, hopes, and fears identified by the patient and/or family that require attention in the plan of care.

**Family** Those closest to the patient in knowledge, care and affection.

May include:

- the biological family
- the family of acquisition (related by marriage/contract)
- the family of choice and friends (including pets).

The patient defines who will be involved in his/her care and/or present at the bedside.

**Goal** A desired future condition:

- statement of intent
- broader in focus than an objective
- specific enough to indicate direction and thrust

- quantitative or qualitative.

**Grief** Sorrow experienced in anticipation of, during and after a loss.

**Hospice palliative care** Care that aims to relieve suffering and improve the quality of living and dying ([see page 17 for more details](#)).

**Illness** Absence of wellness due to disease, another condition, or aging.

An **acute illness** is one that is recent in onset and likely to be time-limited. If severe, it could be life threatening.

A **chronic illness** is likely to persist for months to years. With progression it may become life threatening.

An **advanced illness** is likely to be progressive and life threatening.

A **life-threatening illness** is likely to lead to death in the near future.

**Indicator** A statistical compilation of multiple similar or related performance measures/metrics. It is used to link related organizational issues, to evaluate interrelated leading or lagging indicators, or to effectively reduce the overall number of metrics or measures to a manageable level.

**Interdisciplinary careteam (related to patient / family care)** A team of caregivers who work together to develop and implement a plan of care.

Membership varies depending on the services required to address the identified issues, expectations, needs and opportunities. An interdisciplinary team typically includes one or more physicians, nurses, social workers/psychologists, spiritual advisors, pharmacists, personal support workers, and volunteers. Other disciplines may be part of the team if resources permit.

**Justice** The fair treatment of all individuals, without discrimination or prejudice.

**Life closure** The process of putting personal, social (including financial and legal), and spiritual affairs in order, giving of gifts (eg, personal treasures, money, etc), creation of a legacy, reminiscence, and saying goodbye in preparation for death. This usually occurs close to the end of a person's life.

**Measure** To find out the extent, size, quantity, capacity, etc.

**Mission** A short statement of an organization's purpose; what it is and what it does.

**Needs** Issues identified by caregivers that require attention in the plan of care.

**Nonmaleficence** The avoidance of doing harm.

**Norm** A statement of usual or average practice. Less rigid than a standard.

**Objective** A desired accomplishment or hoped for result:

- specific
- narrower in focus than a goal (may flow from a goal and be a means to achieve a goal)
- quantitative and measurable.

**Outcome** A measurable end result or consequence of a specific action or essential step.

**Pain** An individual, subjective, unpleasant sensory and emotional experience that is primarily associated with tissue damage or described in terms of tissue damage, or both ([Adapted from the International Association for the Study of Pain](#))

**Patient** The person living with an acute, chronic, or advanced illness.

The term **patient**, as opposed to **client**, is used in recognition of the individual's potential vulnerability at any time during the illness. The word **patient** derives from the Latin *patiens*: to suffer, to undergo, to bear.

The patient is a contributing member of the interdisciplinary team.

**Plan of care** The overall approach to the assessment, management, and outcome measurement to address the expectations and needs prioritized as important by the patient and family.

**Policy** A course of action selected from alternatives and in light of given conditions to guide and determine present and future decisions.

<b>Preferred practice guideline</b>	The recommended approach to guide the provision of care related to a particular issue. Must be flexible to take into account the exceptions/ variations needed to meet the wide range of patient/ family expectations and needs. May be consensus or evidence based.
<b>Principle</b>	A fundamental truth.
<b>Provider</b>	A formal caregiver who is a member of an organization and accountable to defined norms of conduct and practice. They may be professionals, support workers, or volunteers.
<b>Procedure</b>	A mode of conducting an activity. Often guided by preferred practice guidelines.
<b>Program</b>	An organization with a number of component parts. It may be part of a larger host organization, or independent. It may or may not have its own governance structure.
<b>Proxy</b>	A person or agency of substitute recognized by law to act for, and in the best interest of the patient.
<b>Quality care</b>	The continuous striving by an interdisciplinary team/ program to meet the expectations and needs of the patients and families it serves.
<b>Quality of life</b>	Well-being as defined by each individual.  It relates both to experiences that are meaningful and valuable to the individual, and his/ her capacity to have such experiences.
<b>Regional team</b>	Regional teams are functional units within hospice palliative care organizations designed to provide formal caregivers and oversight to multiple patient/ family careteams within a given population/ region/ setting of care.
<b>Risk</b>	A measure of the presence of variables that are likely to contribute to the development of an undesirable illness or condition.
<b>Setting of care</b>	The location where care is provided.  Settings for hospice palliative care may include the patient's home, an acute, chronic, or long-term care facility, a nursing home/ skilled nursing facility, a hospice or palliative care unit or freestanding facility, a jail or prison, the street, etc.

- Service** An organization providing assistance or service to others. Services tend to be part of a larger organization (e.g., a host organization or a program). They have one or more component activities. Most will not have their own governance structure.
- Spirituality** An existential construct inclusive of all the ways in which a person makes meaning and organizes his/her sense of self around a personal set of beliefs, values and relationships
- This is sometimes understood in terms of transcendence or inspiration. Involvement in a community of faith and practice may or may not be a part of an individual's spirituality.
- Standard** An established measurable condition or state used as a basis for comparison for quality and quantity.
- Strategies** The specific methods, processes, or steps used to accomplish goals and objectives. Strategies impact resources (inputs) in some positive or negative way. They are executed in a tactical manner so as to link goals and objectives to day-to-day operations
- Suffering** A state of distress associated with events that threaten the intactness of a person. It may be accompanied by a perceived lack of options for coping.
- Tactics** The specific actions that link goals to day-to-day operations.
- Therapeutic relationship** a relationship between skilled caregivers and the patient/family that aims to change the patient's and family's experience of illness and bereavement. It combines the art and science of the process of providing care with the knowledge and skills needed to deliver a wide range of therapeutic interventions
- Total pain** Suffering related to, and the result of, the person's physical, psychological, social, spiritual and practical state.
- Truth-telling** The communication of what is known or believed to be true without deceit or falseness. Patients may voluntarily decline to receive information and designate someone else to receive information on their behalf, as long as there is no evidence of coercion.
- Unit of care** Those who are the focus of a plan of care. In hospice palliative care this is typically the patient and his/her family.
- Value** A fundamental belief on which practice is based.

**Vision** A short statement of an organization's aspirations; what it hopes to become and achieve.

**Volunteer** A person who freely gives of his/her time, talent, and energy.

Volunteers are members of an organization and accountable to that organization's standards of conduct and practice.

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## Additional Resources

URLs were last updated March 23, 2002.

[Canadian Hospice Palliative Care Association](#), 131C - 43 Bruyère Street, Ottawa, Ontario, Canada K1N 5C8. Phone (613) 241-3663, Toll-free in Canada (800) 668-2785, Fax (613) 241-3986.

[Center for Palliative Studies, San Diego Hospice](#).

[International Association for Hospice and Palliative Care](#). c/o UT MD Anderson Cancer Center, 1515 Holcombe Blvd. Box 08, Houston, Texas, USA 77030.

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[Textbook of Palliative Nursing](#). Ferrell BR, Coyle N. New York, NY: Oxford University Press, 2001.

<b>Square of Care</b>		History of issues, opportunities, associated expectations, needs, hopes, fears Examination - assessment scales, physical exam, laboratory, radiology, procedures	Confidentiality limits Desire and readiness for information Process for sharing information Translation Reactions to information Understanding Desire for additional information	Capacity Goals of care Requests for withholding/ withdrawing, therapy with no potential for benefit, hastened death Issue prioritization Therapeutic priorities, options Treatment choices, consent Surrogate decision-making Advance directives Conflict resolution	Setting of care Process to negotiate/ develop plan of care - address issues/ opportunities, delivery chosen therapies, dependents, backup coverage, respite, bereavement care, discharge planning, emergencies	Careteam composition, leadership, education, support Consultation Setting of care Essential services Patient, family support Therapy delivery Errors	Understanding Satisfaction Complexity Stress Concerns, issues, questions
		<b>Assessment</b>	<b>Information-sharing</b>	<b>Decision-making</b>	<b>Care Planning</b>	<b>Care Delivery</b>	<b>Confirmation</b>
<b>PROCESS OF PROVIDING CARE</b>							
Primary diagnosis, prognosis, evidence Secondary diagnoses - dementia, substance use, trauma Co-morbidities - delirium, seizures Adverse events - side effects, toxicity Allergies	<b>Disease Management</b>	<b>C O M M O N  I S S U E S</b>	<b>Patient / Family</b>				
Pain, other symptoms Cognition, level of consciousness Function, safety, aids Fluids, nutrition Wounds Habits - alcohol, smoking	<b>Physical</b>						
Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self esteem	<b>Psychological</b>						
Cultural values, beliefs, practices Relationships, roles Isolation, abandonment, reconciliation Safe, comforting environment Privacy, intimacy Routines, rituals, recreation, vocation Financial, legal Family caregiver protection Guardianship, custody issues Meaning, value	<b>Social</b>						
Existential, transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons	<b>Spiritual</b>						
Activities of daily living Dependents, pets Telephone access, transportation	<b>Practical</b>						
Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals Death pronouncement, certification Perideath care of family, handling of body Funerals, memorial services, celebrations	<b>End of life/ Death Management</b>						
Loss Grief - acute, chronic, anticipatory Bereavement planning Mourning	<b>Loss, Grief</b>						

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<b>Square of Care and Organization</b>		History of issues, opportunities, associated expectations, needs, hopes, fears Examination - assessment scales, physical exam, laboratory, radiology, procedures	Confidentiality limits Desire and readiness for information Process for sharing information Translation Reactions to information Understanding Desire for additional information	Capacity Goals of care Requests for withholding/withdrawing, therapy with no potential for benefit, hastened death Issue prioritization Therapeutic priorities, options Treatment choices, consent Surrogate decision-making Advance directives Conflict resolution
		<b>Assessment</b>	<b>Information-sharing</b>	<b>Decision-making</b>
	<b>PROCESS OF PROVIDING CARE</b>			
Primary diagnosis, prognosis, evidence Secondary diagnoses - dementia, substance use, trauma Co-morbidities - delirium, seizures Adverse events - side effects, toxicity Allergies	<b>Disease Management</b>	<b>C O M M O N  I S S U E S</b>	<b>Patient /</b>	
Pain, other symptoms Cognition, level of consciousness Function, safety, aids Fluids, nutrition Wounds Habits - alcohol, smoking	<b>Physical</b>			
Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self esteem	<b>Psychological</b>			
Cultural values, beliefs, practices Relationships, roles Isolation, abandonment, reconciliation Safe, comforting environment Privacy, intimacy Routines, rituals, recreation, vocation Financial, legal Family caregiver protection Guardianship, custody issues	<b>Social</b>			
Meaning, value Existential, transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons	<b>Spiritual</b>			
Activities of daily living Dependents, pets Telephone access, transportation	<b>Practical</b>			
Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals Death pronouncement, certification Perideath care of family, handling of body Funerals, memorial services, celebrations	<b>End of life/ Death Management</b>			
Loss Grief - acute, chronic, anticipatory Bereavement planning Mourning	<b>Loss, Grief</b>			
		<b>RESOURCES</b>		
		<b>Financial</b>	<b>Human</b>	<b>Informational</b>
		Assets Liabilities	Formal caregivers Consultants Staff Volunteers	Records - health, financial, human resource, assets Resource materials, eg, books, journals, Internet, Intranet Resource directory

From: Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P.

Setting of care Process to negotiate/ develop plan of care - address issues/ opportunities, delivery chosen therapies, dependents, backup coverage, respite, bereavement care, discharge planning, emergencies	Careteam composition, leadership, education, support Consultation Setting of care Essential services Patient, family support Therapy delivery Errors	Understanding Satisfaction Complexity Stress Concerns, issues, questions	
<b>Care Planning</b>	<b>Care Delivery</b>	<b>Confirmation</b>	
<b>PROCESS FOR PROVIDING CARE</b>			
			<b>Governance &amp; Administration</b> Leadership - board, management Organizational structure, accountability
			<b>Planning</b> Strategic planning Business planning Business development
			<b>Operations</b> Standards of practice, policies & procedures, data collection/documentation guidelines Resource acquisition & management Safety, security, emergency systems
			<b>Quality Management</b> Performance improvement Routine review: outcomes, resource utilization, risk management, compliance, satisfaction, needs, financial audit, accreditation, strategic & business plans standards, policies & procedures, data collection/ documentation guidelines
			<b>Communications/Marketing</b> Communication/marketing strategies Materials Media liaison
			<b>F U N C T I O N S</b>
<b>RESOURCES</b>			
<b>Physical</b> Environment Equipment Materials/supplies	<b>Community</b> Host Organization Healthcare System Partner healthcare providers Community organizations Stakeholders, public		

# Family

# Square of Organization

<h2 style="font-size: 2em; font-weight: bold;">Principal Activities</h2>					F U N C T I O N S	<b>Governance &amp; Administration</b>	Leadership - board, management Organizational structure, accountability
						<b>Planning</b>	Strategic planning Business planning Business development
						<b>Operations</b>	Standards of practice, policies & procedures, data/documentation guidelines Resource management Safety, security, emergency systems
						<b>Quality Management</b>	Performance improvement Routine review outcomes, resource utilization risk management compliance satisfaction, needs financial audit accreditation strategic & business plans standards, policies & procedures, data/documentation guidelines
						<b>Communications/Marketing</b>	Communication/marketing strategies Materials Media liaison
						<b>RESOURCES</b>	
<b>Financial</b>	<b>Human</b>	<b>Informational</b>	<b>Physical</b>	<b>Community</b>			
Assets Liabilities	Formal caregivers Consultants Staff Volunteers	Records - health, financial, human resource, assets Resource materials, eg, books, journals, Internet, Intranet Resource directory	Environment Equipment Materials/supplies	Host Organization Healthcare System Partner healthcare providers Community organizations Stakeholders, public			

## Further Information

**A Model to Guide Hospice Palliative Care** is available from The Canadian Hospice Palliative Care Association in both English and French in this printed format, on a CD-ROM, and on the Internet at <http://www.cPCA.net>.

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### Information/Additional Copies

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## Autres renseignements

On peut se procurer le **Modèle de guide des soins palliatifs** en français et en anglais à l'Association canadienne de soins palliatifs, sur papier, sur CD-ROM et sur Internet, à <http://www.acsp.net>.

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### Mention bibliographique

Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. *Modèle de guide des soins palliatifs*. Ottawa, ON: Association canadienne de soins palliatifs, 2002.

### Renseignements et exemplaires supplémentaires

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The standards of practice we create  
And the people we train  
Will look after us  
When it's our turn to receive care ...

Are you ready?"

Frank D. Ferris, 1997

# **A Model To Guide Hospice Palliative Care: Based on National Principles and Norms of Practice**

was developed by members of the

## **Canadian Hospice Palliative Care Association (Ottawa, ON)**

In partnership with the 11 provincial hospice palliative care associations:

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