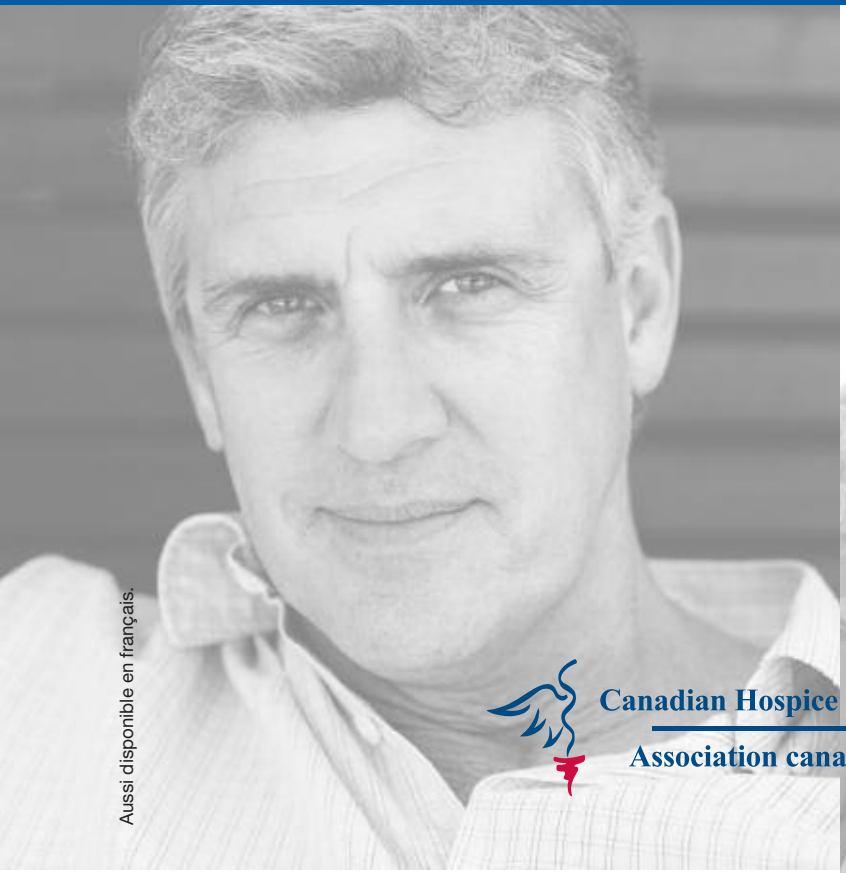
A Model to Guide Hospice Palliative Care:

Based on National Principles and Norms of Practice

Revised and Condensed Edition: 2013



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

Aussi disponible en français.

Production of this document has been made possible, in part, through a financial contribution from the Government of Canada through *The Way Forward* initiative.

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Canadian Hospice Palliative Care Association. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2013.

A revision of Ferris F, Balfour H, et al. A Model to Guide Hospice Palliative Care, 2002.

Disponible en français sous le titre:
Modèle de guide des soins palliatifs : Fondé sur les principes et les norms de pratique nationaux

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Based on National Principles and Norms of Practice
Canadian Hospice Palliative Care Association
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ISBN: 978-1-896495-19-4

Second Printing: June 2004
URL Updates: August 2005
Revision: September 2013

Acknowledgements

The Canadian Hospice Palliative Care Association would like to thank the members of the expert advisory committee who reviewed and provided their input on how to update and streamline the original *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*:

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Preface

A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice (the Norms) was first released in 2002. Over more than ten years, the field has enthusiastically embraced the norms, using them to develop programs that provide high quality comprehensive person and family-centred hospice palliative care.

In 2013, the Canadian Hospice Palliative Care Association (CHPCA) established an expert advisory committee to review and revise the Model to Guide Hospice Palliative Care to reflect current practice and experience. The document has been streamlined to focus on the principles and Norms and provide only the most used information.

The Norms have been revised to emphasize those aspects of care and organization that are unique to hospice palliative care. The goal is the same: to provide consistent high quality care for all Canadians with life-limiting illnesses. We encourage hospice palliative care programs and professionals to continue to use *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* to guide their activities.

The CHPCA will continue to develop and identify tools and resources to help palliative care programs and professionals apply the Norms in their practice and in their organizations. In an effort to streamline this process, all additional resources will be available at **www.chpca.net/norms** instead of as an appendix to this document.

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Background

The practice of hospice palliative care in Canada began in the 1970s and has evolved rapidly, adapting to keep pace with changes in people's experience of illness and dying. Because of medical advances, people now live much longer – years, even decades – with life-limiting illnesses. 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 experiences that enhance quality of life?

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.

Each of these issues creates expectations, needs, hopes and fears, which must be addressed for the ill person to adapt, continue living and find opportunities for growth and meaning in living and dying. For many years, hospice palliative care has focused on helping individuals and their families address these issues in the last few weeks of life. More recently, the palliative approach to care is being applied throughout the illness trajectory to help relieve suffering, improve the quality of life, engage people in their care, potentially prolong life and strive for a comfortable death.

Why a National Model for Hospice Palliative Care?

A national model for hospice palliative care creates a shared vision and a consistent, standardized approach to the delivery of care, organizational development, education and advocacy across the country. A national model will help organizations and programs:

Standardization encourages consistency, however it doesn't imply uniformity. Organizations will continue to differ to some degree in how they develop and function, and in their policies, procedures, and data collection/documentation strategies.

- Ensure that all caregivers and staff are knowledgeable and skilled, and have the support they need to fulfill their roles;
- identify any gaps in care and expand their services or develop partnerships with other health care providers to fill these gaps;
- and manage their activities, resources and functions.

The model can be used to:

- guide care provided for individuals and families by both primary and expert caregivers
- integrate hospice palliative care into chronic disease management
- guide the development and management of hospice palliative care organizations
- develop professional core competencies, comprehensive curricula and examinations
- develop accreditation and minimum licensure standards
- allow organizations to compare their practices to nationally accepted norms of practice
- promote laws, regulations and policies that facilitate hospice palliative care
- develop funding and service delivery strategies that ensure Canadians have access to hospice palliative care when needed.

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Overview of this Document

This document is organized into five sections:

I. The underlying understanding of health and illness

II. The definition of hospice palliative care and the values, principles and foundational concepts that drive all aspects of hospice palliative care

III. A guide to the delivery of person and family-centred hospice palliative care to, including a conceptual framework – the "Square of Care" – which identifies:

- the issues commonly faced by individuals and families during an illness;
- the essential steps in the process of providing care;
- the principles and norms of practice related to each step in the process of providing care.

IV. A guide to organizational development and function, including a conceptual framework – the "Square of Organization" – which identifies:

- the resources required to operate a hospice palliative care organization;
- the principal functions of an organization;
- the principles and norms of practice related to each aspect of organizational function.

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I. The Underlying Understanding of Health and Illness

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

The Illness Experience

When people become ill or frail, their lives change dramatically. They may experience a wide range of issues, including manifestations of the disease (e.g., symptoms, functional and psychological changes), changes in roles and relationships, and losses of opportunity, income and financial security.

Most people do not want the changes that come with illness. They perceive these changes as a threat to their capacity for meaningful and valuable experiences, and to their future quality of life. For many, it may be the first time they face their own mortality.

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.*"[1] State of health is perceived differently by many individuals. 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.

Dr. 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.*"[2] The choices that each person makes and his/her experiences lead to a very personal sense of their quality of life. Quality of life is closely tied to autonomy, and the capacity and right to determine our own future.

Who is Affected by the Illness?

While an illness affects the person, it also affects the person's family (i.e., everyone close in knowledge, care and affection), and anyone who lives or works with the person or provides care. The illness may challenge family roles, leadership and group dynamics. When the person dies, the existing family group changes and a new group forms that may have different dynamics.

If family members can deal with the multiple losses and changes associated with a death, and make the healing transition through their bereavement experience, they can rebuild their lives successfully and reintegrate into society. If their transition is challenging, they may themselves become patients in the health care system and/or struggle to fulfill their roles at home and in the workplace. For society, a family's suffering and the quality of their lives is a public health issue. By relieving suffering and improving quality of life, hospice palliative care aims to promote health and healing – physical, psychological, social and spiritual well-being – for everyone affected by illness and bereavement, including those who provide care.

The Challenge of Hospice Palliative Care: Addressing Complex Issues and Expectations

To relieve suffering and improve quality of life, caregivers must be able to identify and respond to all the complex issues individuals and families may face, which can be categorized into eight equally important domains.

Note: the issues in each domain (Figure 1 on next page) are examples and not an exhaustive list.

If one or more issues are missed, they can compound one another, leading to distress.

Each issue identified by the person 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 are also opportunities for growth. People may face personal issues they had not recognized

[1]World Health Organization (WHO) Definition of Health, http://www.who.int/aboutwho/en/definition.html.

[2] 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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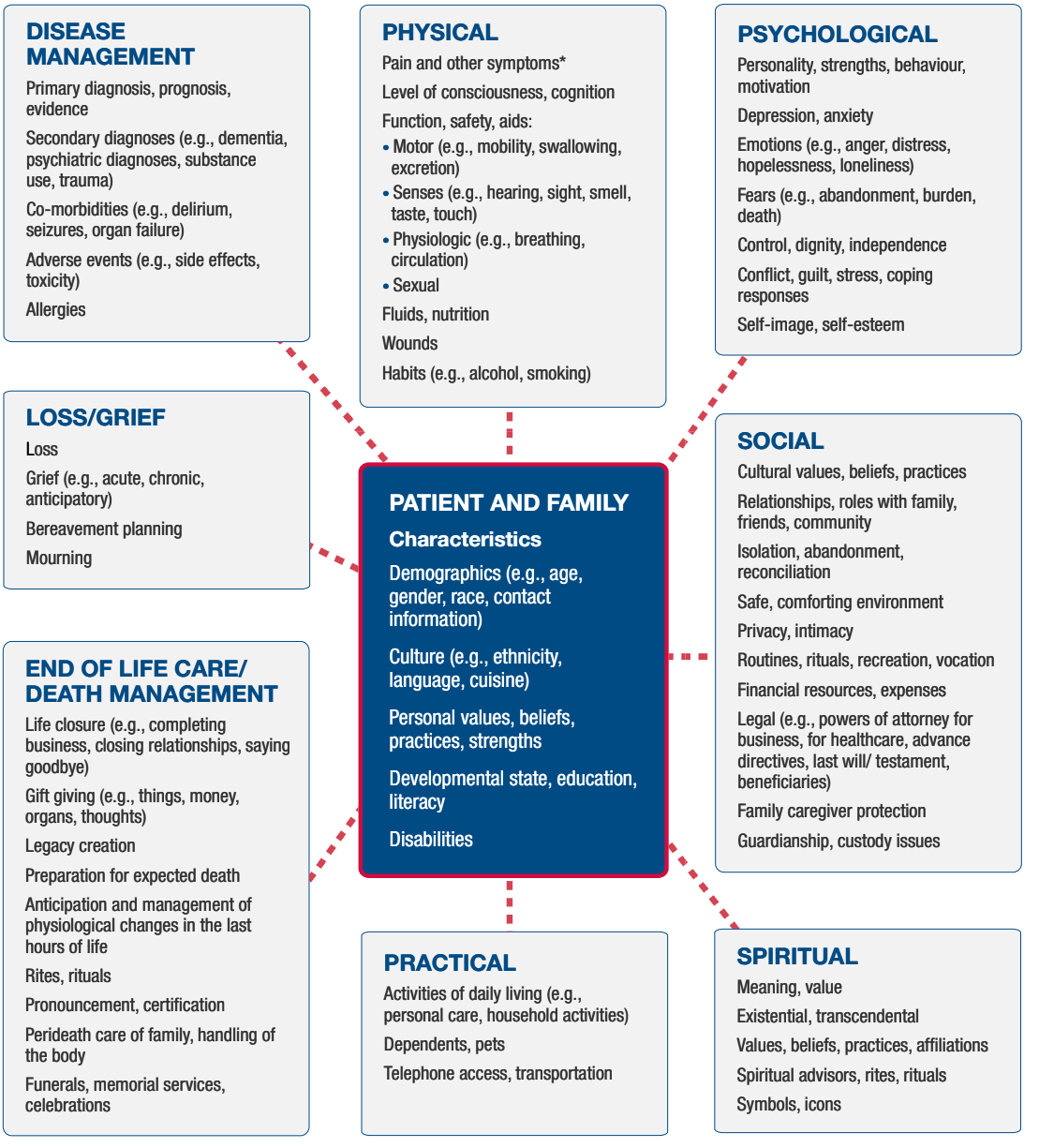
before. They may find new approaches to activities of daily living and their roles and relationships. They may develop a new understanding of life, the future, death and dying.

The practice of hospice palliative care offers a combination of appropriate therapeutic interventions aimed at treating and managing disease, relieving suffering and improving quality of life. With this comprehensive approach, the person's and family's experience of illness and bereavement may be very different, and their future may be closer to what they anticipated.

Figure #1: 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

What is Hospice Palliative Care?

The ***World Health Organization*** defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as part of the normal process of living
- neither hastens nor prolongs death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and throughout their own bereavement
- enhances quality of life, and may also positively influence the course of illness
- is offered early in the course of the illness, in conjunction with other therapies that are intended to prolong life, and includes investigations to better understand and manage distressing clinical complications." (World Health Organization, 2013)

Hospice palliative care engages individuals and their families in planning for the care they want at different stages in their illness based on their own goals and values and on a clear understanding of their prognosis and treatment options (advance care planning). When people have access to palliative care services, they report fewer symptoms, better quality of life, and greater satisfaction with their care. The health care system reports more appropriate referrals, better use of hospice care, fewer emergency room visits and hospitalizations, and less use of ineffective intensive interventions in the last days of life.

The Canadian Hospice Palliative Care Association **(CHPCA)** has developed the following definition to guide hospice palliative care norms and practice in Canada.

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

Hospice palliative care strives to help individuals 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 experience.

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 person 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.

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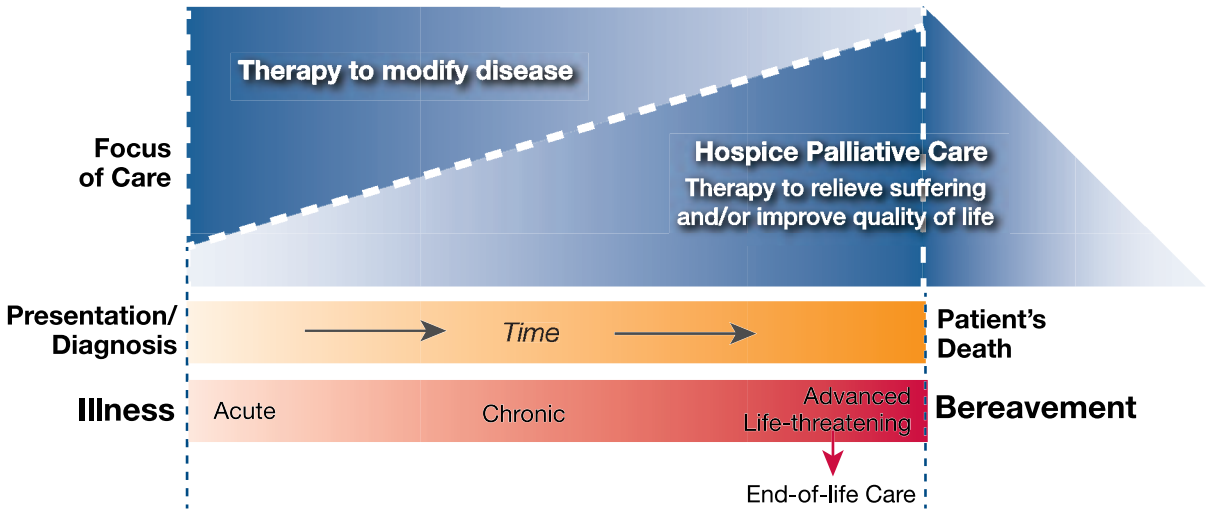
Hospice palliative care is most effectively delivered by an interprofessional team of health care providers who are both knowledgeable and skilled in all aspects of care within their discipline of practice. Providers are typically trained by schools or organizations governed by educational standards and are accountable to standards of professional conduct set by licensing bodies and/or professional associations.

The Role of Hospice Palliative Care Throughout the Illness Trajectory

While hospice palliative care has grown out of and includes care for people at the end of life, today it should be available to individuals and families throughout the illness and bereavement experience. The following figure illustrates the typical shift in focus of care over time, and how hospice palliative care plays an increasingly significant role as the person moves through the illness trajectory.

Figure #2: The Role of Hospice Palliative Care During Illness



At the beginning of the illness, the focus is mainly on therapy to treat or manage the illness, with some support from hospice palliative care that aims to relieve suffering and improve quality of life. Over the course of an illness, the mix of therapies will fluctuate based on the person's and family's issues, their goals of care and treatment priorities.

Some aspects of hospice palliative care may also be helpful for people at risk of developing an illness and their families.

Values Driving Hospice Palliative Care

All hospice palliative care activities are driven by the following values:

1. **Autonomy**. Each person is an autonomous and unique individual. Care is guided by quality of life as defined by the individual. Care is only provided when the person and family are prepared to accept it.
2. **Self Actualization**. Dying is part of living, and both living and dying provide opportunities for personal growth and self-actualization.
3. **Dignity.** Caregivers enter into a therapeutic relationship with persons and families based on dignity and integrity.
5. **Community.** A unified response to suffering strengthens communities.

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Guiding Principles

The following principles guide all aspects of hospice palliative care:

1. **Person/Family Centred**. The person is engaged in and directs his or her care, including deciding how family members will be involved. When care is provided, the person and family (as determined by the person) are treated as a unit. All aspects of care are provided in a manner that is sensitive to the person's and family's personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

2. **Ethical**. All hospice palliative care activities are guided by the ethical principles of autonomy, beneficence, non-maleficence, justice, truth-telling and confidentiality. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdiction.

3. **High Quality.** All hospice palliative care activities are guided by standards of practice based on nationally-accepted principles and norms of practice, and standards of professional conduct for each discipline.

4. **Team-Based/Circle of Care**. Hospice palliative care is most effectively delivered by an interprofessional team of health care providers who are both knowledgeable and skilled in all aspects of care within their discipline of practice. The professional team comes together with family members, friends and other caregivers to form a circle of care around the person and family.

5. **Safe and Effective.** All hospice palliative care activities are conducted in a manner that:
   - ensures confidentiality and privacy
   - is without coercion, discrimination, harassment or prejudice
   - is beneficial and does not create undue risk or burden
   - ensures safety and security
   - ensures continuity and accountability
   - minimizes unnecessary duplication and repetition
   - complies with laws, regulations and policies in effect within the jurisdiction and hospice palliative care organizations.

6. **Accessible.** All individuals and families have equal access to hospice palliative care services:
   - wherever they live
   - at home or within a reasonable distance from their home
   - when they need it.

7. **Adequately Resourced.** The financial, human, information, physical and community resources are sufficient to support the organization's activities and its strategic and business plans.

8. **Collaborative.** Each community's needs for hospice palliative care are assessed and addressed through collaborative efforts/partnerships among organizations and services in the community.

9. **Advocacy-Based**. Regular interaction with legislators, regulators, policy makers, health care funders, other hospice palliative care providers, professional societies and associations, and the public increases awareness of hospice palliative care activities and the resources required to support them.

10. **Evidence-Informed and Knowledge-Based.** The development, dissemination and integration of new knowledge improves the quality of hospice palliative care. All activities are based on the best available evidence. Ongoing education of all persons, families, caregivers, staff and stakeholders is integral to providing and advancing quality hospice palliative care.

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Foundational Concepts

Hospice palliative care is based on three foundational concepts:

1. **Effective Communication** – which is fundamental to both the process of providing care, the team-based approach to person and family-centred care and the efficient function of a hospice palliative care organization. When combined with informed and skilled decision-making, effective communication leads to better care delivery decisions, less conflict, a more effective plan of care, greater person/family/caregiver satisfaction with the therapeutic relationship, fewer caregiver errors, less stress and fewer burnout/retention problems.

2. **Effective Group Function** – which involves a process of group formation and function that includes forming and then move through storming and norming until the group begins performing their tasks effectively together. Each participant plays a role in the circle of care. Whenever the composition of the circle of care changes, the group must re-establish itself by again moving through the stages until it is performing effectively. To be effective, all groups need skilled leadership to facilitate their activities and promote effective group dynamics.

3. **Ability to Facilitate Change** – which means that the interprofessional team must be skilled at maximizing openness and adaptability in the attitudes, knowledge, skills and behaviours of everyone involved in the circle of care. They must also have specific skills to assist individuals and families through the transitions they experience during illness and bereavement. All aspects of organizational development and function, education, research and advocacy are also based on the effective use of change strategies.

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III. The Model to Guide Person and Family Care

The Process of Providing Hospice Palliative Care

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

- a therapeutic relationship (circle of care) between those who provide care and those who receive it,which evolves with time as familiarity, trust and confidence are established
- a therapeutic process that evolves through a series of therapeutic encounters
- the continued affirmation of the person's and family's values and choices
- the understanding that only therapies[3] with a potential for benefit and acceptable risk or burden will be offered
- change strategies.

During each therapeutic encounter, the process for providing care involves six essential steps that guide the interaction between caregivers, and the person and family. While these steps do not need to occur in any specific order, each one must be completed during each therapeutic encounter. *(See Figure 3 on the next page)*

The Circle of Care

Hospice palliative care is most effectively delivered by an interprofessional team of health care providers who form a therapeutic relationship with the person and family. Although members of the interprofessional team may come from different organizations, they are all typically trained by schools or organizations governed by educational standards, and accountable to standards of professional conduct set by licensing bodies and/or professional associations. They collaborate and share information to promote continuity and enhance care delivery to the person. To maintain an effective therapeutic relationship, every effort is made to keep the team consistent and avoid changing members.

The interprofessional team comes together with family members, friends and other caregivers to form a circle of care around the person and family. The circle of care requires leadership from a professional caregiver who is skilled at group formation/function/dynamics as well as care delivery. The circle of care includes (based on the person's wishes):

- the person and family
- the person's primary care and specialist providers
- professional caregivers[4] with the skills to implement the person's and family's plan of care
- "family" caregivers who may be family members (as defined by the person), friends and/or neighbours
- community resources acceptable to the person and family (e.g., spiritual advisors).

All members of the "circle of care" adhere to the principles of confidentiality and privacy and other relevant regulatory and legislative policies and standards. The circle of care continues throughout the illness and bereavement process, adjourning when care is no longer needed.

[3]Therapies include medications, counseling, psychotherapy, integrative therapies (e.g., acupuncture, aroma, art, chiropractic, imagery, massage, music, recreation, relaxation, touch), other non-pharmacological therapeutics, dressings, equipment and supplies.

[4]Formal caregivers on the team may include, but are not limited to: chaplains, dieticians, nurses, pharmacists, physicians, psychologists, social workers, speech pathologists, integrative therapists, occupational therapists, physiotherapists, recreational therapists, volunteers.

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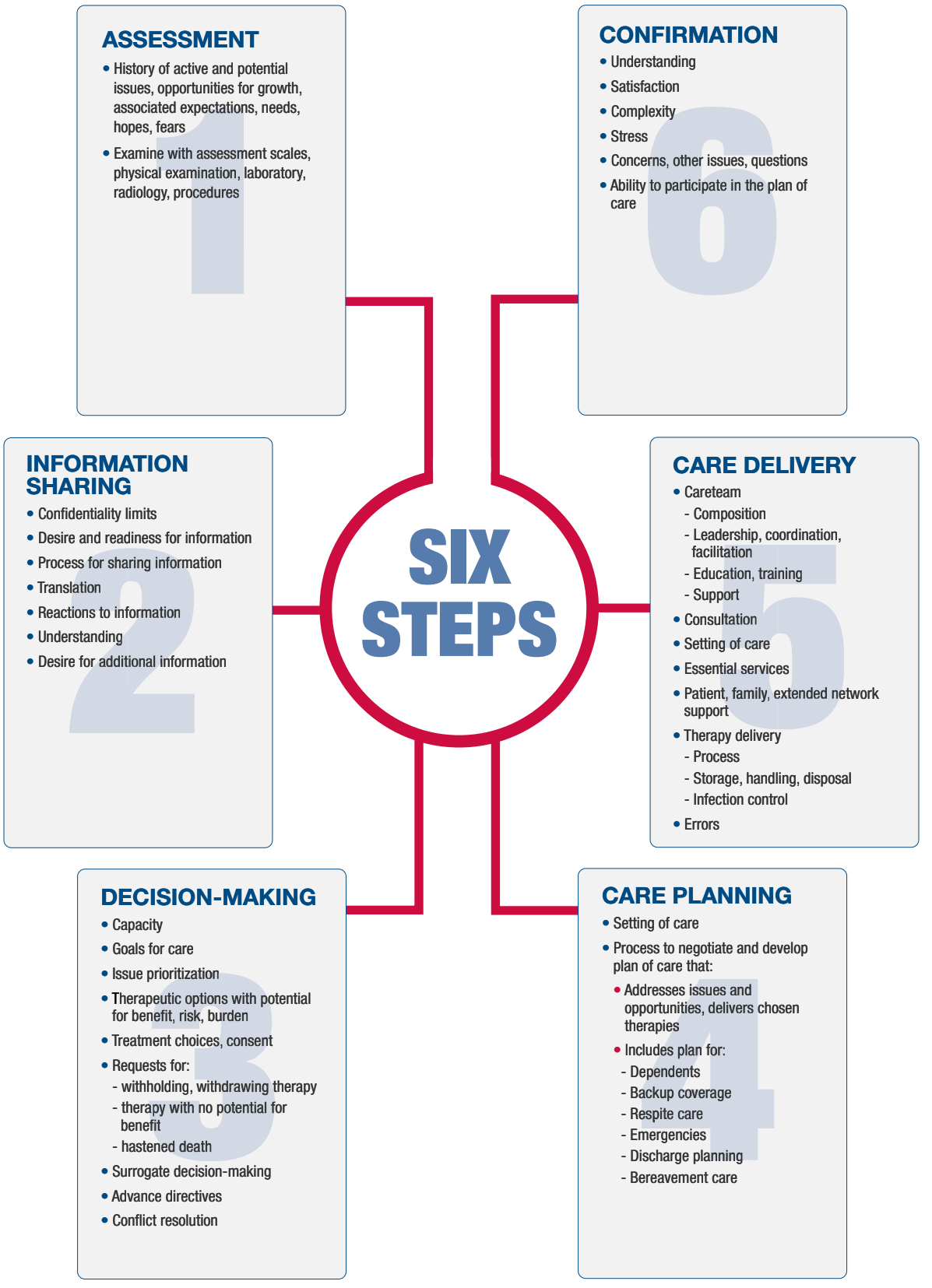
Figure #3: Essential and Basic Steps During a Therapeutic Encounter



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The Square of Care: A Conceptual Framework

The Square of Care is a conceptual framework that reinforces how the process of providing care should address each of the domains/issues commonly faced by persons and families *(see figure 4 on this page)*. The circle of care can use this tool to help identify issues and guide the essential steps of providing care during each therapeutic encounter.

Figure #4: 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			Patient and Family Care			
	Spiritual						
	Practical						
	End of life/ Death Management						
	Loss, Grief						

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

- principles of practice for each essential step
- norms of practice for each step
- preferred practice guidelines for each issue
- data collection and documentation guidelines for each issue.

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

Principles and Norms of Practice

For each essential step in the process of providing care, the CHPCA has developed principles and norms of practice. All programs should strive to achieve the norms of practice at all times. Organizations should use the norms of practice to guide the development of their standards of practice.

1. Assessment

PRINCIPLES

1. Comprehensive assessment is essential to identify and understand the issues, concerns, risks and opportunities related to the person's and family's illness and bereavement experience.
2. Assessments are based on valid relevant information about the person’s and family’s situation gathered, with the person’s permission, from reliable sources (e.g., person, family, friends, professional and family caregivers) and shared within the circle of care.
3. The person’s and family’s needs are reassessed at regular intervals throughout the illness trajectory to provide accurate, up-to-date information to guide decision-making and care planning.

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NORMS OF PRACTICE

1. The interprofessional team conducts a comprehensive assessment, using validated assessment tools and covering all domains of care, to identify all issues (unresolved or new) and opportunities important to the person, family and caregivers.
2. The interprofessional team reassesses the person's and family's issues and needs throughout the illness trajectory, particularly when there is a change in the person's condition.
3. All assessments are documented following relevant regulatory standards.

2. Information-sharing

PRINCIPLES

1. It is the interprofessional team's responsibility to offer and share information about hospice palliative care and what it can offer throughout the illness and bereavement experience with the person and, with the person's permission, the person's family.
2. It is the person'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, and alternatives.
3. Communication within the circle of care respects the limits of confidentiality set by the person or his/her substitute decision maker. Hospice palliative care programs share information only with the person's permission and in compliance with privacy legislation in their jurisdiction.

NORMS OF PRACTICE

1. Limits of confidentiality are defined by the person (or his/her substitute decision maker if the person is not capable) and by relevant legislation before information is shared.
2. The interprofessional team establishes what the person and family already know, what they would like to know, and whether they are ready to listen before sharing information.
3. Information that is as accurate as possible is shared:
   - as it becomes available
   - only in settings where privacy can be ensured
   - only with those entitled to the information
   - in a language and manner understandable and acceptable to the person and family.
4. When language is a barrier, translators who understand the medical concepts and terminology facilitate information sharing within the circle of care.
5. The person's and family's emotional and physical reactions to information, their understanding of the information and its implication, and their desire for any other information are assessed regularly, and responded to effectively and appropriately.

3. Decision-making

PRINCIPLES

1. The person is the custodian of his or her own care.
2. The person:
   - has the right to make informed decisions based on available appropriate therapeutic options, determine goals of care and establish priorities for present and future care
   - must give informed, voluntary consent for any therapy before it is initiated
   - may change her/his mind at any time and may request to have any therapy withdrawn at any time
   - may designate a Substitute Decision Maker, and specify when that person will act on his/her behalf if he/she becomes incapable of making decisions (in compliance with the laws in the jurisdiction).

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3. All decision-making processes respect the limits of confidentiality established by the person or his/her Substitute Decision Maker.
4. Family members are included in decision-making processes at the request of the person or his/her Substitute Decision Maker.

NORMS OF PRACTICE

1. The person's decision-making capacity is regularly re-assessed and document throughout the illness trajectory as his/her condition changes.
2. A person with a life-limiting illness is encouraged (subject to provincial legislation) to:
   - designate a Substitute Decision Maker to make care decisions in the event he/she is unable to do so
   - specify under what circumstances the Substitute Decision Maker should act
   - participate in advance care planning, which includes discussions about their wishes, which are documented to guide the Substitute Decision Maker in the event the person becomes incapable.
3. The person is offered therapeutic options to modify the disease, relieve suffering and improve quality of life that:
   - are appropriate for the person's disease and prognosis, care goals, priority issues and the presumed etiologies of those issues
   - have the potential for benefit
   - are not associated with unacceptable risk or burden as determined by the person or Substitute Decision Maker and care team.
4. The person or Substitute Decision Maker is assisted to make informed decisions about treatment priorities from the options offered, and to give informed consent before treatment is initiated. Therapies, therapeutic options and choices are reviewed regularly.
5. Difficult issues raised by the person, Substitute Decision Maker or family are discussed openly within the circle of care. These issues may include withholding or withdrawing therapies, initiating therapeutic interventions that appear to have no potential benefit, and requests to hasten death (i.e., euthanasia or assisted suicide).
6. All members of the circle of care respect the person's decisions to pursue, have, withhold or withdraw therapeutic interventions. There is a process in place to resolve conflict that is acceptable to the person, family members and caregivers (e.g. family meetings, social work involvement/counseling, ethics referrals).

4. Care Planning

PRINCIPLES

1. Care planning is person and family-centred, holistic and encompasses all domains and issues, taking into account the person's and family's culture, personalities, emotional status, coping strategies, developmental state and pre-existing comorbidities, including mental health diagnoses.
2. Each plan of care is customized, flexible and aims to:
   - support the importance, meaning and roles of each person in the circle of care
   - support the person'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
   - encompass both the person's and family's care goals.

NORMS OF PRACTICE

1. The plan of care is negotiated and developed with the person, family (at the person's request) -- and the care team.

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2. The plan of care includes care goals as well as strategies to:
    - address each of the person's and family's issues or opportunities, expectations, needs, hopes and fears, and deliver their chosen therapies
    - provide care for dependents (e.g., children, elders, pets)
    - provide backup coverage if members of the circle of care are unable to fulfill their role in the care plan
    - provide respite for family caregivers
    - cope with emergencies
    - plan for discharge from a facility or program
    - provide bereavement, loss and grief care.
3. The person and, at the person's request, the family are assisted to select an appropriate setting of care.
4. The person's care plan, goals of care and setting are reassessed regularly throughout the illness trajectory, using a person-centred approach. The results are documented and the care plan is revised based on the reassessment.

5. Care Delivery

PRINCIPLES

1. Care is provided by a circle of care (professional and family caregivers) formed to care for each person/family unit.
2. Each circle of care has access to the leadership and resources it needs to facilitate the team's formation and function, and coordinate care planning to deliver care.
3. All aspects of care are prioritized and delivered in a safe, timely manner, including:
    - requests for initial assessment and ongoing follow-up
    - implementation of decisions
    - access to chosen therapies, equipment and supplies
    - access to skilled appropriate expert consultation.
4. Urgent/emergent situations are responded to rapidly.
5. All care is provided in a manner that
    - respects the person and family and their choices
    - is understandable and acceptable to the person and family
    - maintains their sense of dignity
    - maintains their privacy
    - provides ample opportunity for intimacy.
6. The person is active in the delivery of care as long as he/she has the capacity, capability and competency to do so.
7. The circle of care strives for continuity in terms of:
    - the delivery of the plan of care
    - sharing of information across all settings of care and among all caregivers and organizations who are part of the circle of care
    - the individuals providing care.
8. To ensure all aspects of care are provided, partnerships are created among the hospice palliative care organization, other health care providers and community resources.

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NORMS OF PRACTICE

1. Family and friends who are part of the circle of care receive the information they need to provide care, including:
   - education and support in their decision-making to become family caregivers
   - orientation, ongoing training and support to be competent and confident to provide care
   - informational resources, including who to call for support and questions.
2. Family caregivers receive the physical, psychological and spiritual support and assistance they need to provide effective care, ensure their own well-being and adapt to changes that occur throughout the person's illness trajectory.
3. Resources are engaged as needed to assist the interprofessional team and circle of care with ethical issues, specialized investigations, therapeutic interventions or activities (e.g., rites and rituals).
4. The setting of care is safe, comforting and provides ample opportunity for privacy and intimacy. Where possible, settings of care are homelike, with access to the outdoors.
5. Access to services is available 24 hours per day, 7 days per week.
6. All therapeutic interventions are delivered in a safe manner that:
   - is consistent with health and safety legislation and the organization's standards of practice and policies and procedures
   - is acceptable to the person and family
   - optimizes their potential for benefit
   - minimizes the potential for medication interactions, adverse effects or undue burden
   - is consistent with manufacturer's/supplier's instructions.
7. All medications are:
   - stored safely
   - administered by those qualified to do so safely and with full knowledge of their desired and potential effects and compatibilities
   - discarded appropriately if they are damaged, outdated, expired or no longer required.
8. All equipment and supplies are stored and maintained so that they are stable and safe for use. No equipment is used that is expired or in need of repair.
9. 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 according to legislation where applicable.
10. An infection control program guides all clinical activities.
11. Any error in therapy delivery:
    - is reported to the appropriate authority immediately
    - has an appropriate antidote started as quickly as possible where applicable
    - is discussed openly with the person or Substitute Decision Maker and the family (if requested by the person)
    - is documented appropriately.
12. All approaches to delivering care are reviewed regularly and adjusted to compensate for changes in the person's and family's status and choices.

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6. Confirmation

PRINCIPLES

1. The person's or Substitute Decision Maker's understanding, satisfaction, sense of complexity, level of stress, concerns, questions and desire for additional information are assessed and addressed during each therapeutic encounter.

NORMS OF PRACTICE

1. By the end of each therapeutic encounter, the interprofessional team confirms that the person or Substitute Decision Maker – and family members, at the request of the person — understand:
   - the situation
   - the plan of care
   - the goals of care
2. By the end of each therapeutic encounter, the interprofessional team ensures that everyone understands what is going on by assessing and, if necessary, addressing the person's or Substitute Decision Maker's (and family's, if requested by the person):
   - satisfaction with the process of providing care and the overall situation
   - perception of the complexity of the situation
   - perception of the level of stress
   - concerns, questions and desire for additional information
   - ability to participate in the plan of care.

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IV. The Model to Guide Organization Development and Function

The Nature of Hospice Palliative Care Organizations

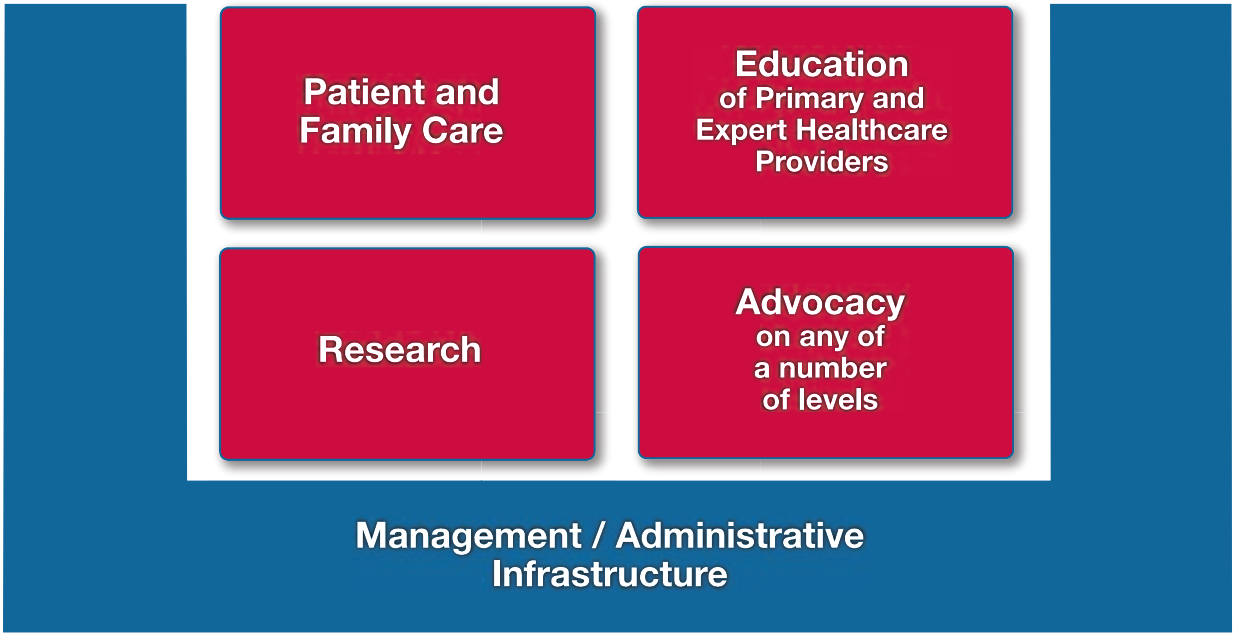
To support the process of providing care, hospice palliative care organizations must have a management and administrative infrastructure to develop and maintain the resources needed to support its principal activities and functions.

Mission and Vision Statements

To help identify/define their activities and functions, organizations usually develop a mission and a vision statement. A mission statement sets out the organization's purpose (i.e., what it is and what it does).

A vision statement describes the organization's aspirations (i.e., what it hopes to become and achieve in the future).

Figure #5: The Principal Activities of Hospice Palliative Care



Resources

To undertake its principal activities, a hospice palliative care organization must develop and maintain a number of key resources *(see figure 6 on next page)*

Principal and Basic Functions

To develop and manage these resources, a hospice palliative care organization must implement five principal functions. *(see figure 7 on next page)*

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Figure #6: Resources to Support Hospice Palliative Care

Financial Resources	Human Resources	Information Resources	Physical Resources	Community Resources
Assets • Cash • Capital • Investments • Receivables **Liabilities** • Payables • Depreciation • Taxes **Insurance**	**Formal caregivers** • Bereavement counselors • Chaplains • Dietitians • Integrative therapists • Nurses • Occupational therapists • Pharmacists • Psychologists • Physicians • Physiotherapists • Psychologists • Social workers • Speech pathologists • Support workers • Volunteers (caregivers) • Consultants (e.g., ethics, clinical, legal, administrative) **Staff** • Administration • Support **Volunteers (non-caregivers)**	**Records** • Health • Financial • Human resource • Assets **Resources** • Resource, reference materials, (e.g., books, journals) • Internet, Intranet **Resource directory**	**Environment** • Space • Lighting • Heating, cooling • Utilities • Parking **Equipment** • Medical • Diagnostic and investigative • Office • Communication systems, (e.g., telephones, pagers, e-mail) • Information technology systems, (e.g., computers, printers, networks, internet access) • Security systems **Materials, Supplies** • Medical • Office • Other	**Host organization** **Healthcare system** **Partner healthcare providers** **Community organizations** **Faith/religious communities** **Stakeholders** **Public**

Figure #7: Hospice Palliative Care Principal and Basic Functions

Governance & Adminstration	Planning	Operations	Quality Management (Evaluation)	Communications /Marketing
Leadership • Board • Management **Organizational structure/ accountability**	**Strategic plan** • Needs assessment • Mission, vision • Values, purpose, principal activities • Goals, objectives, strategies, tactics • Timelines, strategic decision points **Business plan** • Organizational/ accountability structure • Resource acquisition and management • Implementation • Quality management • Communications, marketing **Business development**	**Standards of practice, policies and procedures, standards for data collection/ documentation** **Resource acquisition and management:** • Fund development – stewardship, annual program, foundation and research grants, planned giving • Financial resources - billing, accounting, banking, dispersement • 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 • Informational resources - data collection, purchasing, storage, maintenance, reporting, destruction • Physical resources - purchasing, stock control,maintenance, disposal • Community resources - relationship building, contracting, relationship management, contract/ relationship termination **Safety, security, emergency systems**	**Performance improvement** • Outcomes • Resource utilization • Adverse events, including errors, complaints • Satisfaction **Routine review** • Utilization review, clinical outcomes and resource utilization • Risk management • Compliance • Caregiver and employee satisfaction • Community needs • Financial audit • External accreditation • Strategic and business plans • Standards of practice, policies and procedures, standards for data collection/documentation	**Communication and marketing strategies** **Materials** **Support for fundraising** **Media liaison** **Adverse situations**

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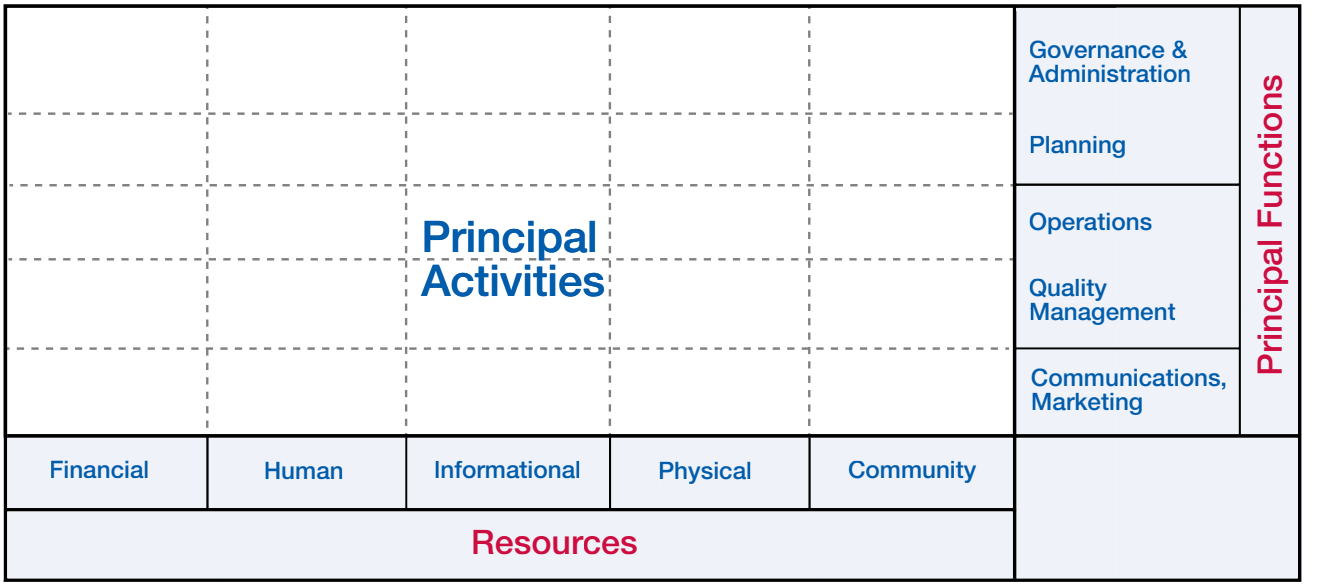
Square of Organization: A Conceptual Framework

The conceptual framework – the "Square of Organization" *(see Figure 8)* – illustrates how an organization applies the functions to develop and maintain its resources. Like the "Square of Care," this framework can be used to guide the development of the organization's infrastructure.

Figure #8: The Square of Organization



Principles and Norms of Practice

For each of an organization's five principal functions, the CHPCA has developed principles and norms of practice. [*Note: the numbering continues from the principles and norms of practice in the previous section.*]

7. Governance and Administration

PRINCIPLES

1. Governance and administration are essential to the development, implementation, operation and accountability of organizations providing hospice palliative care.
2. Governance includes senior leadership and representatives of the organization(s), community, professional and family caregivers, persons and families.

NORMS

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

8. Planning

PRINCIPLES

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

NORMS

1. The organization has an overarching strategic direction that guides the development of its infrastructure and principal activities.

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2. The organization has a business plan to guide the development of the resources and functions needed to support its infrastructure and activities. The business plan includes:
   - a governance and administrative structure
   - a plan to acquire/manage each of the needed resources
   - a plan to implement each of the principal activities and the infrastructure
   - a quality improvement plan/initiatives
   - a plan to meet accreditation standards
   - a communications/marketing plan.

9. Operations

PRINCIPLES

1. All the organization's activities are guided by legislation/regulation and by evidence-informed standards of practice, policies and procedures, and data collection/documentation practices.
2. Governance and fiscal diligence are essential to sustain the organization's activities over the long term.
3. It is essential to attract, retain, orient, train and support talent (staff and volunteers) who have the knowledge, competency, skills and judgment to provide hospice palliative care.
4. Work-life balance is essential to ensure the physical, psychological and spiritual well-being of staff and volunteers.
5. A safe healthy work environment and appropriate physical resources are essential to provide hospice palliative care.

NORMS OF PRACTICE

1. The organization uses the best available preferred practice guidelines, which are based on evidence or expert opinion, to guide its policies and procedures.
2. The organization uses validated or the best available measurement tools to guide its data collection/documentation guidelines.
3. The organization maintains the governance and other accountability measures required by legislation to ensure fiscal diligence and fulfill its strategic and business goals.
4. The organization has policies and procedures to guide fundraising activities, stewardship, budgeting, billing, accounting, banking and the dispersal of funds (including expenses, salaries/benefits, and taxes) – including policies to address any concerns or suspected wrongdoing – that are consistent with its mission, vision and values and with relevant legislation and regulations.
5. The organization has policies and procedures in place to attract, retain, support and manage the talent[5] it needs to support its activities including credentialing, orientation and education, staff support, staffing, incentive/recognition programs, and employment termination/ outplacement.
6. The organization's staff and volunteers reflect the cultural diversity of the community it serves.
7. The organization provides ongoing educational opportunities to build and maintain the capacity and competency of the members of the circle of care.
8. The circle of care has the knowledge and support required to maintain effective boundaries within therapeutic relationships.
9. The organization has an ongoing program to engage employees and volunteers, assess their satisfaction and address any issues.

[5]Talent include professional caregivers as well as caregiving volunteers, consultants, management and support staff, and non-caregiving volunteers.

10. The organization continuously works to identify and minimize occupational risks and hazards.

11. The organization has a process to incorporate new knowledge/evidence into practice.

12. The organization has the physical space and facilities to support its activities.

13. The organization has policies and procedures to develop and maintain formal relationships with community resources across the continuum of care.

11. Quality Improvement

PRINCIPLES

1. A quality improvement process that includes all aspects of the organization's activities, resources and functions is essential to ensure quality.
2. Compliance with all legislation, regulations and policies governing hospice palliative care is an integral part of quality improvement.

NORMS OF PRACTICE

1. The organization has an ongoing program to improve quality, including indicators that measure outcomes, resource utilization, adverse events (e.g., medication and other therapeutic errors, complaints) and stakeholder satisfaction.
2. The organization:
   - regularly reviews outcome and resource utilization data to inform its activities
   - regularly assesses customer and community hospice palliative care needs, whether those needs are being met and satisfaction with the organization's services
   - has a risk management program, and a process to review and respond to adverse events and complaints
   - has a review program to ensure that it complies with legislative and regulatory mandates
   - participates in intermittent accreditation reviews to assess its effectiveness compared to other similar organizations, and the CHPCA norms of practice.

11. Communications/Marketing

PRINCIPLES

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

NORMS

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.
2. Information about the organization, its activities, and how to access its services is readily available to individuals, families and the public.
3. The organization has a communication strategy to support its fundraising.
4. The organization has a media strategy that includes communication through social media.

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V. Data Collection and Documentation

Data collection and documentation are integral to providing high quality hospice palliative care and to operating effective organizations. Hospice palliative care organizations and programs must have the capacity to collect data and use that data to document services, evaluate their outcomes, assess quality, and inform planning, resource allocation, advocacy and quality improvement initiatives.

12. Collection and Use of Data

PRINCIPLES

1. Organizations collect data on and document all their activities.
2. Every therapeutic encounter is documented.
3. The data collected is clinically useful.
4. The task of collecting data is practical, not repetitive and not burdensome.

NORMS OF PRACTICE

1. Operational records and accounts are kept according to legislation, and are readily accessible to support the provision of care.
2. Clinical data are collected and documented at each therapeutic encounter and reflected in the person's current plan of care.
3. After each therapeutic encounter, the interprofessional team documents:
   - the presence or absence of each commonly-occurring issue
   - the status at a "point in time" of each active issue
   - the interventions during the encounter
   - the effectiveness of the interventions.
4. Information is collected and documented in a way that reflects the standards of practice of provincial regulatory bodies and is consistent with provincial regulations and standards.
5. Information is collected in a format that is easy to review as part of quality improvement initiatives and readily identifies errors and risks.
6. If the process used during the encounter follows accepted policies and procedures, only the status and outcomes of the process need to be documented. If the process varies from accepted policies and procedures, it should be documented as well.
7. The organization has the information and resources required to support its activities, and policies and procedures to guide the purchasing, storage, maintenance and disposal of information that are consistent with provincial and federal legislation.
8. The organization has policies and procedures that reflect current legislation/regulation to guide:
   - the collection, storage and reporting of health and other information to support care delivery and quality management
   - ready and appropriate access to the information
   - the destruction of its health, financial, human resource and asset records.

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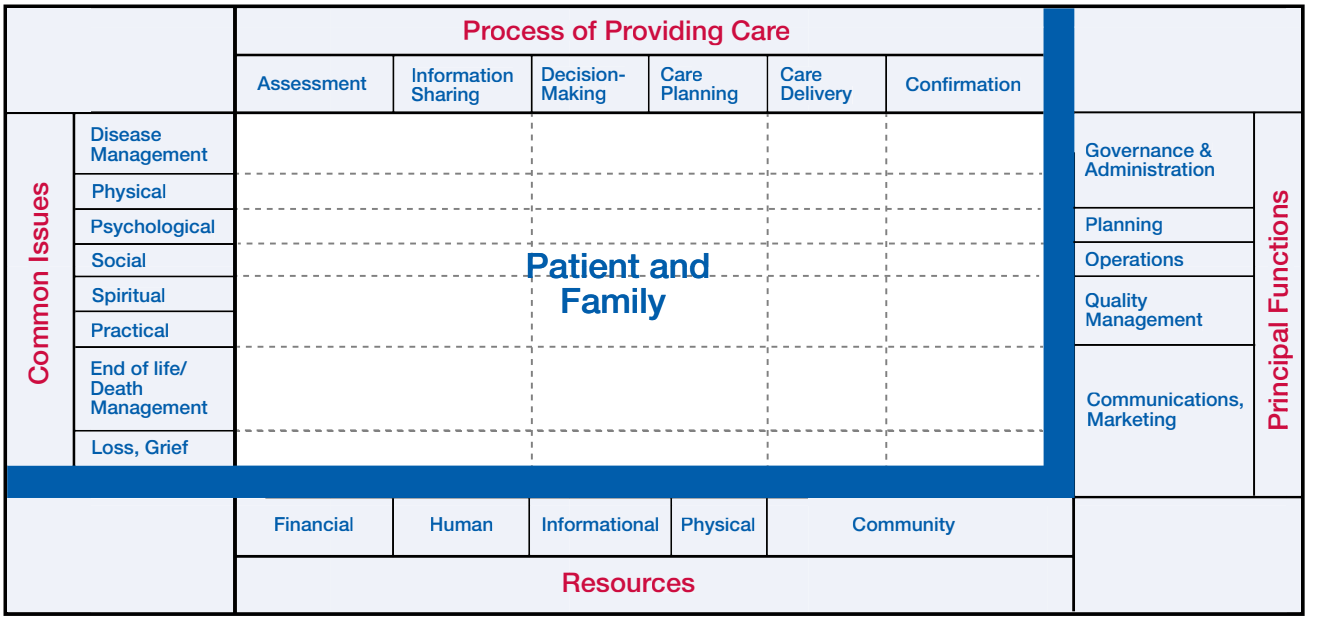
Conclusion

Modern medicine has markedly changed the experience of illness and bereavement. Today, people are living for much longer with multiple issues related to underlying disease, conditions or aging. In the process, they may experience prolonged suffering and changes to the quality of their lives, which affects them, their families and their communities.

By applying the model described in this document – summarized in the square of care and organization (Figure 9) below — hospice palliative care organizations can be more effective at relieving suffering and improving quality of life. In addition, persons and families can realize their full potential to live more fully and comfortably until they die.

Figure #9: The Square of Care and Organization



In the end, our society's ability to realize its potential is related to its success in integrating hospice palliative care early into all settings within the health care system, across the continuum of care and trajectory of illness, to relieve suffering and improve the quality of living and dying.

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