

**HOSPICE PALLIATIVE CARE  
NURSING STANDARDS OF  
PRACTICE**

*“This work is dedicated to those persons and families who, through their suffering and loss, have motivated us to improve our knowledge, skills and understanding in order to bring greater peace and comfort to those who have entrusted and who will entrust their care to us in the future”*

CPCA Nursing Standards Committee

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**TABLE OF CONTENTS**

Introduction	5
History of hospice palliative care nursing in Canada	7
Vision	8
Mission	8
Purpose	8
Philosophical Beliefs	9
Framework for hospice palliative nurse	11
Canadian standards of hospice palliative care nursing	14
Standard I – Valuing	14
Standard II – Connecting	15
<i>Making the connection</i>	15
<i>Sustaining the connection</i>	15
<i>Closing the connection</i>	16
Standard III – Empowering	16
Standard IV – Doing for	18
<i>Pain and symptom management</i>	18
<i>Coordination of care</i>	21
<i>Advocacy</i>	22
Standard V – Finding meaning	22
Standard VI – Preserving integrity	23
<i>Self</i>	23
<i>Person and family</i>	24
Glossary	25
References	26
Bibliography	27

## INTRODUCTION

Palliative Care, according to the World Health Organization, is the “active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable in the course of the illness...” (year?) The Canadian Palliative Care Association (CPCA, 1995) broadens the definition of palliative care to incorporate, “the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with, or dying from, a progressive life-threatening illness, or are bereaved.”

Palliative care:

- affirms life and regards dying as a normal process;
- neither hastens nor postpones death;
- provides relief from pain and other distressing symptoms;
- 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 in their own bereavement.

At some time, in some way, everyone will face the end of life. Those working in palliative care share a common hope, that when the end of life comes to us or to a loved one, it will be peaceful and free of pain, surrounded by those we love, feeling cared for and safe.

The assessment and management of pain and other symptoms associated with advanced illnesses has improved. Despite these advances the burden of suffering for Canadians remains quite high with a small number of Canadians having access to integrated and interdisciplinary palliative care.

More than 650 programs and services in the hospice palliative care network in Canada are providing care (CPCA, 2001). Since the first programs began in 1974, thousands of Canadians have been helped to live fully during the last stages of their lives. Hospice palliative care nurses have been and still remain committed to providing quality end of life care to persons and their families. The emphasis of care is on the “whole person” with symptom management as a well recognized and integral part of hospice palliative care service delivery.

The person and family are identified as the unit of care, emphasizing their physical, emotional, psychosocial and spiritual needs. This practice is accomplished through an interdisciplinary team approach that provides comprehensive, coordinated and compassionate care in all care settings.

In 1993, a special interest group for hospice palliative care nurses met in Winnipeg for the first time, establishing a formal network that met at subsequent national and international palliative care conferences. The purpose of these meetings was to further develop hospice palliative care nursing in Canada. The goal of the network was to establish a national voice, which would help to identify, address, and advocate for recognition of hospice palliative care nursing as a speciality requiring advanced knowledge and clinical skills. The development of nursing standards in conjunction with the Canadian Nurses Association (CAN) and CPCA Standards of Practice will serve as the basis of hospice palliative care nursing certification in Canada.

## HISTORY OF HOSPICE PALLIATIVE CARE NURSING IN CANADA

The role of the nurse has been an integral component of the modern hospice palliative care movement since its inception in Canada in the 1970's. Influenced by the development of hospice care at St. Christopher's in England, the first palliative care services were opened November 1974 at St. Boniface Hospital, Winnipeg, Manitoba closely followed by the Royal Victoria Hospital, Montreal, Quebec in January, 1975. Since that time, hospice palliative nursing care has been developed and continues to be provided in a multitude of settings through integrated and specialized palliative care services. Improving care for persons and families is contingent upon changing systems of care. Nursing has a tremendous opportunity to influence change in current systems of care.

The Canadian Palliative Care Association (CPCA) is the only national voice of hospice palliative care. Founded in 1993, it is a charitable non-profit association. The mission is to lead the pursuit of excellence in care for persons approaching end of life so that the burdens of suffering, loneliness and grief are lessened.

CPCA strives to achieve its' mission through:

- Collaboration and representation
- Increased awareness, knowledge and skills related to hospice palliative care of the public, health care providers and volunteers
- Development of national standards of practice for hospice palliative care in Canada
- Support research on hospice palliative care
- Advocacy for improved hospice palliative care policy, resource allocation and support for caregivers

CPCA has a national board of directors composed of 11-provincial/territorial hospice palliative care associations and 5 members at large. The fast growing membership includes more than 2200 nurses, physicians, health care managers, counsellors, social workers, volunteers and family members in Canada and abroad. The members serve thousands of Canadians and their families facing life threatening illness and bereavement. The national office is in Ottawa.

The CPCA vision is to ensure that all Canadians have access to compassionate end of life care. Each year, more than 220,000 Canadians die. This means that more than 1,000,000 Canadians are affected by life threatening illness each year. It is estimated that only 5% of these Canadians have access to hospice palliative care services. CPCA wants all Canadians to have access.

The current CPCA consensus building process (2001) regarding standards (norms) of practice has guided the development of hospice palliative care nursing standards.

## **VISION**

All persons and their families living with and dying from advanced illness will have access to nurses who provide knowledgeable and compassionate care to lessen the burden of suffering and improve the quality of living and dying.

## **MISSION**

Hospice palliative care nurses bring specialized knowledge, skills and attitudes to the delivery of comprehensive, coordinated and compassionate care to all persons and families living with advanced illness. The focus is on quality of life throughout the illness continuum, dying, and bereavement. Care is provided in the setting of the person and family choice. Hospice palliative care nursing has a commitment to public and professional education, leadership, research and advocacy in caring for the person and family living with advanced illness.

## **PURPOSE**

The purpose of hospice palliative care nursing standards in Canada is to:

- Establish requisite knowledge for the nursing care of persons and families with advanced illness.
- Support on-going development of hospice palliative care nursing.
- Promote hospice palliative care nursing as a specialty.
- Serve as a foundation for the development of certification in hospice palliative care nursing.



## **PHILOSOPHICAL BELIEFS**

Fawcett (1984) found a consensus in the nursing literature that identifies person, environment, health, and nursing as the fundamental units which are of the greatest importance to nursing. The philosophical beliefs of hospice palliative care nursing are organized below according to these fundamental units. These beliefs and the Code of Ethics for Registered Nurses (1999) provide the basis of the nursing framework and the care provided by the hospice palliative care nurse.

### **Person**

“You matter because you are you and you matter to the last moment of your life. We will do all we can to help you, not only to die peacefully but to live until you die.”

(Cicely Saunders, St Christopher’s Hospice London. (year?))

The hospice palliative care nurse believes:

- A dignified and peaceful death is the right of all persons.
- In the intrinsic value of each person as an autonomous and unique individual.
- The person and their family, living with advanced illness, are the unit of care.
- The person includes individuals from all ages and stages across the lifespan, recognizing their unique physical, emotional, social and spiritual needs.
- Hospice palliative care services should be available to all persons regardless of their age, gender, national and ethnic origin, geographical location, race, color, language, creed, religion, sexual orientation, diagnosis, disability, availability of a primary caregiver, ability to pay, criminal conviction, and family status.
- The person and family have the right to make informed decisions about all aspects of care, respecting the level of participation desired by the person and family.

### **Environment**

The hospice palliative care nurse believes:

- Care should be provided, as much as possible, in the setting chosen by the person and family.
- Care should be provided at the primary, secondary, and tertiary levels, in the community, acute care, and long term/continuing care settings in urban, rural and remote areas. Community care settings include local hospitals, hospices, homes, lodges, prisons, group homes, rehabilitation centers, and specialized facilities such as psychiatric facilities and cancer centers.
- Care is best provided through the collaborative practice of members of an interdisciplinary team to meet the physical, emotional, social and spiritual needs of the person and their family living with advanced illness.
- Care spans the continuum from diagnosis until death of the person and includes the bereavement period for the family.

## **Health**

The hospice palliative care nurse believes:

- Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (WHO, 1990).
- In the value of life and that death is a natural process.
- Health for the person with advanced illness is a relative and dynamic state with the person experiencing varying states of wellness/life until the moment of death.
- Each person and/or family defines their quality of life.
- Facing death may be a personal or spiritual growth experience for each person.
- Health promotion, in the setting of advanced illness, relates to quality of life and involves assisting persons to achieve their optimum state of health and well-being during illness and in the natural process of dying.

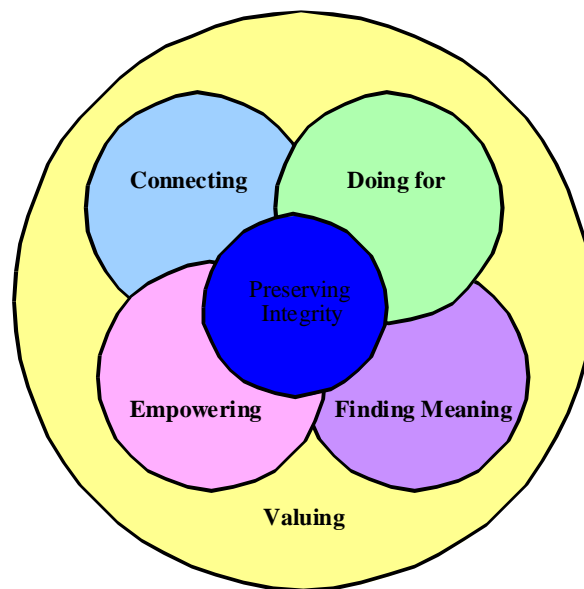
## **Hospice Palliative Care Nursing**

The hospice palliative care nurse believes:

- Nurses have a unique and primary responsibility for advocating for the right of persons to maintain their quality of life for as long as possible and to experience a dignified and peaceful death.
- Exemplary care is provided to persons and their families living with advanced illness through the therapeutic relationship.
- Care is guided by best practice and/or is evidence-based.
- Care respects the dignity and integrity of the person and family.
- Hospice palliative care nursing provides comprehensive, coordinated, compassionate whole person care including the physical, emotional, social and spiritual domains.
- Specialized knowledge, skill, and attitude are integral components to providing comfort and supportive care to persons and their families living with advanced illness.
- The unique body of knowledge of hospice palliative care nursing practice includes pain and symptom management, psychosocial support, and grief and bereavement.
- Hospice palliative care nursing includes all areas of practice: clinical, education, administration, research and advocacy.
- The ethical principles of autonomy, beneficence, non-maleficent, justice, truth telling and confidentiality are integrated into the provision of care and program development.
- Education, research and advocacy for the development and maintenance of public policy, palliative care standards, and resources are essential to improve the delivery of palliative care.
- Hospice palliative nursing care is active in the application of knowledge, skills and attitudes and is not passive in nature.

## FRAMEWORK FOR HOSPICE PALLIATIVE CARE NURSING

The Supportive Care Model (Davies & Oberle, 1990) was adapted to clearly reflect hospice palliative care nursing practice and then adopted as the framework for hospice palliative care nursing. The original model was developed through analysis of the care provided by a supportive care nurse who worked in a Pain and Symptom Control Clinic. The analysis identified six interwoven dimensions that make up the clinical portion of the nursing role in palliative care. The six dimensions are: valuing, connecting, empowering, doing for, finding meaning, and preserving integrity (Davies & Oberle, 1990). These dimensions are depicted below as interconnected circles with “valuing” as the outer circle, which underlies all nursing practice and “preserving integrity” as the centre circle which is the heart of hospice palliative care nursing practice. Although intertwined, each dimension is described separately.



### Valuing

"Valuing" is the dimension that provides the context for supportive care (Oberle & Davies, 1992). "Valuing" includes a global component which involves respect for the worth of all humans, as well as a particular component which involves respect for a particular individual based on recognition of their characteristics and abilities. "Valuing" is primarily an attitude rather than an action (Oberle & Davies, 1992).

### Connecting

The dimension of "connecting" involves making a connection with the person and family, sustaining the connection and then breaking the connection (Davies & Oberle, 1990). Davies and Oberle (1990) suggest that some degree of connecting must occur before one can empower, but the connection must also be maintained throughout the process. In making the connection the nurse would begin to build a trusting relationship by taking time to get to know the person/family, establishing credentials, explaining the roles of the team members, getting a baseline assessment, explaining how to contact the nurse, finding a common bond and establishing rapport with the person and family, and communicating effectively. In order to

sustain the connection the nurse would be available and spend time with the family, maintain confidentiality and privacy, and give of self. Nurses continue to provide bereavement support to families after the death of a patient but over time the connection is broken.

### **Empowering**

The dimension of "empowering" involves helping the patient and family to uncover and build on their own strengths (Oberle & Davies, 1992). The components of "empowering" include assessing the family, assessing and supporting the person and family's coping style, assisting with decision making and supporting choices made by the family, assisting the family to deal with ethical dilemmas, allowing the family to vent and defuse frustrations, assisting in healing relationships, and giving information on all aspects of care.

### **Doing for**

The fourth dimension in the Supportive Care Model is "doing for" which is entwined with "empowering". The goal of "doing for" is to free up the person and family to focus energy in the areas that are most empowering for them. The key is in finding a balance between "doing for" and "empowering". This balance can be accomplished by collaborating with the family to identify expectations and goals, and develop a plan of care, and by maintaining a belief in the family's strength and ability to ultimately find their own solutions.

The actions taken in "doing for" include pain and symptom management, co-ordination of care, and advocating for the rights of the person and family (Davies & Oberle, 1990). In providing pain and symptom management the nurse conducts a comprehensive assessment of pain and other symptoms using valid and developmentally appropriate tools. The nurse collaborates with the person, family and interdisciplinary team to develop and implement a plan of care to manage pain and other symptoms, with particular attention to anticipating symptoms and/or side effects and managing symptoms in the final hours of life. Co-ordination of care involves collaborating with and taking a leadership role in the interdisciplinary team, facilitating communication to smooth transitions between different care providers or care settings, assisting the person and family to access resources as needed, and facilitating the necessary procedures that occur at the time of death (pronouncement, transportation of the deceased, support for family, etc.). Advocating for the rights of the person and family includes activities on a global level to educate others and improve services and resources available to the person and family, as well as activities to advocate for the rights of a specific person and family to obtain necessary equipment or services, to have a voice as part of an interdisciplinary team and to deal with legal issues.

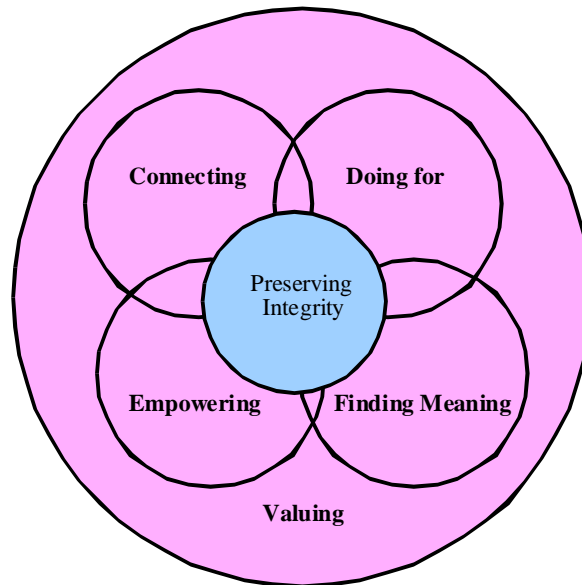
### **Finding meaning**

The dimension of "finding meaning" involves helping the person and family make sense of their situation which is "strength-giving, and therefore empowering" (Davies & Oberle, 1990, p. 92). Davies and Oberle (1990) suggest "finding meaning" involves focussing on living and making the best of the situation by offering hope, as well as acknowledging and talking about death.

## Preserving integrity

The final dimension, which is the core of the Supportive Care Model, is "preserving integrity". This dimension refers to both the integrity of the nurse and the integrity of the person or family (Oberle & Davies, 1993). For the nurse, this dimension includes the ability to maintain self-worth and self-esteem in order to continue effective functioning (Davies & Oberle, 1990). The integrity of the nurse is preserved by providing support through "connecting", "empowering", "finding meaning", and "doing for" but there must also be some replenishing and sustaining activities on the part of the nurse to maintain the energy to carry out these four dimensions. Zerwekh (1995) suggests that the nurse must first take care of self by learning to give and receive, learning to grieve, putting aside personal agendas, replenishing oneself, and staying healthy. Other activities that support the nurse's ability to provide care include reflecting on personal values and beliefs, maintaining a current knowledge base in hospice palliative care through education and research activities, and by dealing with ethical issues as they arise.

Preserving the integrity of the person and family is considered the goal of nursing care and is accomplished by providing support through all dimensions of the Supportive Care Model (Oberle & Davies, 1993). For example, if a nurse only focuses on the dimension of "doing for" the family, other psychosocial and spiritual needs, which are met primarily through the other dimensions, are dismissed. This dismissal may threaten the integrity of the person and family.



## CANADIAN STANDARDS OF HOSPICE PALLIATIVE CARE NURSING

The six dimensions of the Supportive Care Model provide the framework around which the Canadian Standards of Hospice Palliative Care Nursing have been developed. These nursing standards are reflective of the CPCA 2001 Proposed Norms of Practice for hospice palliative care, but are a specific guide for nursing practice which clearly identifies the role of the hospice palliative care nurse as a member of the interdisciplinary team.

### **Standard I - Valuing**

**The hospice palliative care nurse believes in the intrinsic worth of others, the value of life and that death is a natural process.**

The hospice palliative care nurse:

- Advocates that all persons and families with advanced illness have access to available resources.
- Provides care in a nonjudgmental and nondiscriminatory manner that is sensitive to persons and families diversity.
- Empowers persons and families to be active participants in their plan of care.
- Acknowledges whole person care with an understanding of the individual's unique characteristics and abilities.
- Assists the person to find meaning in their unique life and illness experience.
- Assists the person to achieve the best quality of life as defined by the person.
- Acknowledges that death is natural life progression.
- Recognizes and preserves the integrity of self and others.
- Collaborates in creating a social change in the way society views death and dying.

➤ **Standard II: Connecting**

**The hospice palliative care nurse establishes a therapeutic connection (relationship) with the person and their family through making, sustaining and closing the relationship.**

**Making the Connection**

The hospice palliative care nurse:

- Recognizes personal attitudes, feelings, and values regarding death.
- Creates an atmosphere to facilitate trust.
- Seeks to understand the person and family's perspective, their expectations and needs.
- Communicates in a skillful and sensitive manner.
- Listens actively as an integral part of communication.
- Explains the role of nursing and other interdisciplinary team members.
- Assesses the influence of cultural and spiritual values, beliefs, traditions, lifeway patterns of the person and family on their illness experience.

**Sustaining the Connection**

The hospice palliative care nurse:

- Uses skills in verbal and non-verbal communication, listening and presence.
- Responds to the expressed expectations and needs of the person and family.
- Demonstrates a sense of true presence by continual, unconditional acceptance and tolerance.
- Encourages and supports the expression of feelings, perceptions and fears.
- Respects confidentiality and privacy.
- Respects the persons and family's specific care requests.
- Respects the different emotional needs of the person and their family.
- Remains vigilant with respect to maintaining professional boundaries.

- Demonstrates a comfort level in communicating with the person and family about issues related to death and dying.
- Initiates discussions with the person and family about issues related to meaning, implications of diagnosis and prognosis, dying and death.
- Responds in a timely, sensitive, honest manner to the person and family's questions and concerns. **Helps persons and families to establish priorities.**
- Reviews regularly the disease progression, goals of care and treatment with the person, family and team and adjusts plan accordingly.

### **Closing the Connection**

The hospice palliative care nurse:

- Assists the person and family to prepare for and manage the end of life event.
- Demonstrates in-depth knowledge of grief and bereavement care.
- Assists the family in the process of grief and bereavement.
- Recognizes the need for self-closure and healing.
- Prepares the family for the eventual closure of the nurse-family relationship.

### **Standard III – Empowering**

**The hospice palliative care nurse provides care in a manner that is empowering for the person and family.**

The hospice palliative care nurse:

- Identifies priorities for care based on the person and family's perspective.
- Assists the person and family to identify and build on their own strengths.
- Assists the person with advanced illness to address sensitive, personal issues related to sexuality and intimacy.
- Demonstrates knowledge of the broad range of emotions associated with changing body image and self-esteem.
- Establishes a plan of care in collaboration with the person and family.
- Assesses the person and family's learning needs and style.



- Respects the person and family's desire to seek therapies not offered in the conventional health care system.
- Assists the person and family to gather relevant information about the costs, risks and benefits of treatment and end-of-life care in order to make informed decisions.
- Supports informed choices that the person and family have made including withholding treatment, withdrawing life-sustaining therapies.
- Identifies and supports the person and family's coping style.
- Demonstrates awareness of techniques of conflict resolution.
- Collaborates with the person and family to address ethical dilemmas.
- Understands the influence of family dynamics on the illness continuum.
- Assists the person and family to recognize and respect each other's points of views.
- Assists the person and family in memory making and reminiscing.
  
- Provides relevant information appropriate to the developmental level of the person and family such as:
  - Disease process and progression of advanced illness.
  - Options for care and available resources and services.
  - Basic pain and symptom assessment and management.
  - Physical care and emotional support of the person during the progression of the advanced illness.
  - Medications: action, side effects, administration.
  - Treatments: purpose, benefits, adverse effects.
  - Emergencies and complications: opioid toxicity, delirium, spinal cord compression, superior vena cava syndrome, seizures, hypercalcemia.
  - Grief and bereavement: type of grief responses (anticipatory and normal), how to cope with grief, potential reactions of family and friends (including children).

- The dying process: signs and symptoms of imminent death, coping strategies and how to provide support and comfort during the final hours.

#### **Standard IV – Doing for**

**The hospice palliative care nurse provides care based on best practice and/or evidence-based practice in the following areas: pain and symptom management, coordination of care and advocacy.**

##### **Pain and symptom management**

The hospice palliative care nurse incorporates accepted principles of pain management into his/her delivery of care.

The hospice palliative nurse:

- Identifies the multi dimensional factors that influence the person’s ‘total’ pain experience.
- Recognizes that each person’s experience of pain is unique.
- Collaborates with person, family and team to develop an effective plan to manage pain through the use of pharmacological interventions.
- Demonstrates knowledge of the special considerations of children and the elderly.
- Demonstrates an understanding of the various types of pain and pain syndromes and their importance in the effective management of pain.
- Demonstrates the knowledge of the pathophysiology of pain.
- Uses the WHO three step analgesic ladder (1990) as a standard model for pain management.
- Identifies the barriers and myths related to opioid use (e.g. addiction).
- Demonstrates knowledge of opioids which are the basis of pain management.
- Demonstrates knowledge of the side effects of opioids and their management.
- Teaches the person and family the principles of pain management.

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## Assessment

- Conducts a comprehensive pain assessment.
- Assesses tolerance of pain, intervenes as required for persons and family reluctant to complain.
- Uses age appropriate, valid assessment tools in initial pain assessment and for ongoing evaluation.
- Assesses for and implements appropriate measures to treat side effects or complications (e.g. opioid toxicity, myoclonus, urinary retention, delirium).
- Recognizes the symptoms that may require medical intervention.
- Anticipates and develops measures that address potential side effects (e.g. nausea, vomiting, constipation).
- Demonstrates knowledge of indications for opioid rotation
- Assesses for and intervenes in psychosocial and spiritual issues related to pain.
- Collaboratively develops an effective plan to manage pain safely through use of non-pharmacological interventions considering complementary/alternative therapies.

## Management

- Recognizes the critical need for attention to special populations such as children, the elderly and the poor.
- Administers the medications and or techniques that are appropriate to the severity and specific types of pain.
- Monitors on a regular basis the amount of breakthrough medications needed in 24 hours.
- Administers medications in doses sufficient to control the pain and in intervals appropriate to the medication duration of action.
- Demonstrates knowledge of equianalgesic conversions when medications are changed.
- Demonstrates knowledge regarding the combined use of opioid and adjuvant medications for more effective analgesia.
- Demonstrates understanding of the pharmacological and physiological use of adjuvant medications in managing pain in advanced disease (e.g. non-steroidal anti-inflammatory drugs (NSAID's), corticosteroids, anti-convulsants, anti-depressants, antipsychotics).

- Enhances medication delivery by recognizing the use of the oral route as the preferred method of administration.
- Demonstrates knowledge of pain management philosophy by administering medications around the clock (ATC), at regular intervals, and by providing breakthrough dose medication.
- Demonstrates knowledge of opioid rotation.
- Demonstrates awareness of drug availability and costs.
- Demonstrates knowledge of drug interactions and compatibility with other medications.
- Evaluates the effect of the medication and/or side effects and revises plan accordingly.
- Demonstrates knowledge of the unique pain and symptom management strategies in the last hours of life.

The hospice palliative care nurse follows the principles of symptom management.

The hospice palliative care nurse:

- Conducts a comprehensive assessment of symptoms.
- Uses age appropriate valid assessment tools in initial symptom assessment and for ongoing evaluation.
- Collaborates with the person and interdisciplinary team to develop a symptom management plan.
- Demonstrates knowledge to assess and alleviate to the greatest extent possible the following common symptoms:
  - Cardio-respiratory: dyspnea, cough, edema, hiccoughs
  - Gastrointestinal: candidiasis, mucositis, nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, ascites, dehydration, incontinence, jaundice
  - General: anorexia, cachexia, fatigue, sleep disturbances, weakness, bleeding, odour, pruritus, bladder spasms, urinary retention, skin breakdown, seizures
  - Cognitive: agitation, delirium, confusion, depression

- Psychosocial and Spiritual: anxiety, fear, angst, grief
- Manages the symptoms in the final hours of life (e.g., mouth care, anxiety and insomnia, myoclonus, seizures, lymphoedema and decubitus ulcers, excess terminal respiratory secretions).
- Anticipates and recognizes signs and symptoms for common emergencies: spinal cord compression, superior vena cava obstruction, cardiac tamponade, hemorrhage, seizures, hypercalcemia.

## Coordination of care

The hospice palliative care nurse:

- Assists to maintain the person's functional capacity and control and independence.
- Informs person and family how to access services 24 hours/day.
- Modifies plan of care to accommodate socioeconomic factors resulting from unique issues of advanced illness.
- Assesses and monitors the family's willingness, availability and ability to support the person in the home environment throughout the continuum of the person's illness.
- Assesses and responds to environmental safety risks.
- Assesses the appropriateness of the home environment in preparation for end-of-life care and/or home death.
- Teaches regarding safe disposal of supplies/equipment (e.g., opioids, syringes, needles).
- Monitors safe disposal of supplies/equipment.
- Provides information regarding funeral practices/preparation.
- Facilitates effective communication between person, family and careproviders.
- Makes referrals to appropriate interdisciplinary team members.
- Participates in advanced careplanning (e.g., advance directives, life support, DNR status).
- Assumes a leadership role in coordinating the work of the interdisciplinary team.
- Promotes continuity of care and services.
- Arranges for medical equipment, supplies, or medications.
- Facilitates and coordinates transfer to a different level of care or care setting.
- Coordinates person and family conferences.
- Initiates and participates in interdisciplinary team conferences.
- Facilitates arrangements for pronouncement, notification of death or transportation of deceased.

- Facilitates transition into bereavement services.

### **Advocacy**

The hospice palliative care nurse:

- Advocates and defends the rights of the person and family recognizing their vulnerability.
- Intercedes on behalf of person and family with appropriate services whenever necessary.
- Assists the person and family in identifying and dealing with relevant legal issues (e.g., personal directives, power of attorney, proxy).
- Demonstrates the need for increased services.
- Encourages person and family role in interdisciplinary team decisions.
- Educates the public and other health care providers on end-of-life issues and hospice palliative care.

### **Standard V – Finding meaning**

**The hospice palliative care nurse assists the person and family to find meaning in their life and their experience of illness.**

The hospice palliative care nurse:

- Assists the person to feel balance and connection with self, others, all life or higher power as appropriate.
- Promotes dignity and integrity.
- Is a catalyst to finding meaning and hope.
- Demonstrates in-depth knowledge of the concept of hope.
- Assists the person and family to maintain a sense of control.
- Assists the person and the family to manage the emotional response to the illness experience.
- Supports the person and family in coping with the uncertainty related to the illness.
- Assists the persons and families to clarify beliefs and values as appropriate.
- Ensures that the persons and families have access to the appropriate resources to meet and address their spiritual needs.

- Assists the person and family to maintain hope for the future acknowledging that the focus of hope is constantly changing.

## **Standard VI - Preserving Integrity**

**The hospice palliative care nurse preserves the integrity of self, person and family.**

### **Self**

The hospice palliative care nurse:

- Recognizes signs of stress that lead to caregiver burnout and identifies strategies for dealing with stress.
- Demonstrates in-depth knowledge of the historical evolution of the modern hospice palliative care movement worldwide.
- Demonstrates knowledge of the current principles and practices of palliative care.
- Identifies personal values, beliefs, and reactions related to life, death, spirituality, culture, ethnicity, and religion.
- Acknowledges how personal values and beliefs impact on practice.
- Recognizes personal values and beliefs and ensures they do not interfere with the provision of care.
- Demonstrates value of self by practicing self-care.
- Recognizes and takes appropriate measures to cope with multiple losses and grief reactions.
- Balances own self-care needs with the complexities and intensities of death and dying.
- Participates in ongoing educational activities related to hospice palliative nursing and hospice palliative care.
- Applies knowledge gained through education about hospice palliative care by making appropriate changes in practice.
- Participates in research activities appropriate to the individual's position, education and practice environment.
- Practices in a manner that reflects the Code of Ethics for nursing.



- Adheres to national and provincial legislation as well as agency policies and procedures.
- Integrates the CPCA standards into practice.
- Engages in discussions and identifies strategies to resolve ethical concerns related to end of life.

### **Person and family**

The hospice palliative care nurse:

- Provides **active** comprehensive, compassionate, coordinated care.
- Recognizes that even with the provision of excellent palliative care, the loss of a loved one creates intense grief.
- Integrates palliative care as a health promotion activity at the person, family and community level.
- Supports the family caregiver(s) in practicing self care activities to prevent a deterioration of health.
- Recognizes signs of stress that lead to family caregiver burnout and assists the family to identify strategies for dealing with stress.

## GLOSSARY

**Advanced illness:** An illness that is life threatening and likely to be progressive.

**Advocacy:** The act of working on behalf of the person and their family in order to promote their autonomy.

**Bereavement:** State of having suffered a significant loss through death.

**Comprehensive coordinated care:** Is service that integrates key dimensions in palliative care related to pain and symptom management, supportive care and grief and bereavement care. The care is guided by an identified interdisciplinary team member who assumes lead in linking the services and the caregivers (both formal and informal) across all care settings.

**Family:** Those closest to the person 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 person defines who will be involved in his/her care and/or present at the bedside.

**Lifeways:** Are established patterns within the family unit that illustrates their valuing of certain rituals, traditions and beliefs.

**Person:** The individual living with advanced, progressive illness.

**Quality of life:** Well being as defined by the person living with advanced illness. It is the gold standard for palliative care.

**Team:** Caregivers who work together to provide care to the person and their family, based on an interdisciplinary model.

**“Total Pain”:** Suffering related to, and the result of, the person’s physical, psychological, social, spiritual and practical state.

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