

# **Pediatric Oncology Palliative Care Guidelines**



**BC Children's Hospital  
Division of Pediatric Oncology/Hematology/BMT**

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## Preface

In British Columbia, about 120 children are diagnosed with cancer each year. In spite of great advances in curing childhood cancer, inevitably some will die. Each year approximately 25 children, from newborn to 19 years of age, die of cancer or its treatment in BC. The emotional, social and financial impact of these deaths is extraordinary. A child's death is a painful, sorrowful loss for parents, siblings, extended family members, teachers, health care caregivers, volunteers and others. During the dying journey, children and their families suffer from reduced quality of life, loss of family income, inconsistency in the availability and quality of hospice palliative care, and the lack of true choices about where the child may die.

The following table shows the number of deaths in the Oncology/Hematology/SCT program at Children's Hospital, from 2000-2004, and place of death.

	2000	2001	2002	2003	2004
<b>Home</b>	8	5	7	5	6
<b>Community Hosp.</b>	7	8	6	6	3
<b>3A/3B</b>	3	2	4	2	2
<b>ICU</b>	3	7	4	3	3
<b>Canuck Place</b>	7	9	6	6	6
<b>Total</b>	28	31	27	22	20

Until recently, hospice palliative care had focused predominantly on the needs of adults who are dying, and the needs of children have been overlooked. This is changing. Groups such as Children's International Palliative Projects and Services (ChIPPS), the Canadian Hospice Palliative Care Association Pediatric Interest Group [Canadian Network of Palliative Care for Children (CNPCC)], and the Initiative for Pediatric Palliative Care, have brought together leaders in the field to share ideas and advance the field of pediatric hospice palliative care. Other groups have concentrated on the specific needs of children with cancer who are dying of their disease or treatment-related complications, such as the Association of Pediatric Oncology Nurses and the Children's Oncology Group.

Over the past year, members of the Oncology/Hematology/SCT program at BC Children's Hospital have worked to adapt the Canadian Hospice Palliative Care Association's (CHPCA) national principles and pediatric norms of practice for the pediatric oncology population. We think this document describes our pediatric oncology palliative care practice. Our next steps will be to use this document to plan care with our partners throughout the province. It is a first step to establishing standards of practice, service delivery, program and policies for pediatric oncology hospice palliative care, regardless of whether that care is delivered at home, in a hospital, or in a hospice. Its goal is to promote a standard, consistent approach to pediatric oncology hospice palliative care in British Columbia. We believe that a standard approach to pediatric oncology hospice palliative care will help to:

- ensure all families have access to high quality care
- make caregivers and organizations more effective at identifying family issues, the care required, and the resources required to provide that care

- ensure all caregivers are knowledgeable and skilled, and have the support they need to fulfill their roles
- identify any gaps in care and encourage caregivers to expand their services or develop partnerships with other caregivers to fill the gaps.

## Suggestions for Using this Document

Everyone providing pediatric oncology hospice palliative care is encouraged to use the principles and norms set out in this document to **guide** their activities. Norms are simple statements that describe the “usual” or “normal” practice. We plan to use the norms to develop more detailed, measurable standards. For example, the norm for assessing a child and family’s need for pediatric hospice palliative care is a fairly general statement:

*“Assessment is comprehensive and timely so clinicians have adequate information to guide the plan of care.”*

An organization would then establish minimum standards that caregivers must meet to achieve that norm. For example:

*“The assessment will be done using (name of assessment form). All questions must be completed.”*

*“The assessment will be done within 24 hours of the child being referred to the program.”*

While working from common principles and norms encourages consistency, it doesn’t imply uniformity. Organizations will differ in the way they develop and function, and in the policies, procedures and strategies they develop to guide their practice.

*Norms of Practice for Pediatric Hospice Palliative Care, March 2004*

## Acknowledgements

This document has been adapted from the CHPCA Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice, *Norms of Practice for Pediatric Hospice Palliative Care*; March 2004. Much of the content is taken directly from this document, which can be viewed on the Canadian Network for Palliative Care in Children: [www.cpncc.com](http://www.cpncc.com).

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# Background

## What is pediatric hospice palliative care?

Pediatric hospice palliative care is an active, holistic approach to care which focuses on relieving the physical, social, psychological and spiritual suffering experienced by children and families who face a progressive, life-threatening condition, and helping them fulfill their physical, psychological, social and spiritual goals. Its philosophy is to provide optimal comfort and quality of life, and sustain hope and family connection despite the likelihood of death. Pediatric hospice palliative care aims to provide comprehensive care for children and their families through the living, dying and grieving processes. It affirms life and regards dying as a process that is a profoundly personal experience for the child and family. Pediatric hospice palliative care is planned and delivered collaboratively by an interdisciplinary team. It is a child and family centred approach to care that is based on shared decision-making and sensitivity to the family's cultural and spiritual values, beliefs and practices. *(Adapted from the Canadian Hospice Palliative Care Association, and Precepts of Palliative Care for Children/Adolescents and Their Families, 2003).*

Pediatric oncology hospice palliative care addresses the needs of children with cancer for whom cure is no longer possible. Basic principles and guidelines are similar to those in pediatric hospice palliative care.

## How does hospice palliative care for children differ from hospice palliative care for adults?

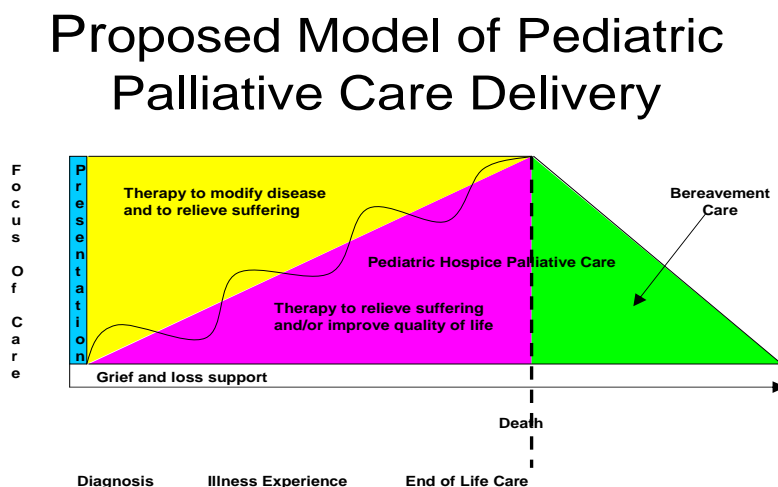
Pediatric hospice palliative care is based on the same principles as adult hospice palliative care but also recognizes the unique needs of families faced with a child's illness and death.

- Children and adolescents are in a process of physical, emotional, cognitive and spiritual development. Depending on their developmental stage, they have different skills and different emotional, physical and development issues/needs.
- Children and adolescents communicate differently, and their understanding of illness, death and dying depends on their stage of development. Health care professionals understand that a child's concepts of illness and dying continue to evolve over time, and develop in association with life and illness experience (Bluebond-Langner, 1978; Eiser, 1995). Religious/cultural beliefs, patterns of coping, disease experience, previous experience with loss/death, sadness, and other emotions associated with grief, all influence a child's understanding of death (Eiser, 1995; McConnell & Frager, 2003; Work Group on Palliative Care for Children, 1999; Committee on Bioethics and Committee on Hospital Care, 2000).
- Children are members of many communities, including families, neighbourhoods and schools, and their continuing role in these communities should be incorporated into their dying journey. School is an integral part of their lives, and it is essential they have ongoing opportunities to pursue education.
- Children respond differently to therapies and drugs. They experience unique symptoms, such as fatigue, nausea, vomiting, shortness of breath, depression and anxiety, which are not well understood. They experience and express pain differently than adults, and require individualized treatment.
- Children are not as able to advocate for themselves, and often rely on family members to make decisions for them.

- Many life-threatening conditions that affect children are rare and only affect children. Many of the illnesses are familial and may affect more than one child in the family. The diseases are often unpredictable in terms of prognosis, and children may require years of caregiving.
- Parents bear a heavy responsibility for the care of their child, which may include making decisions in the best interest of the child at a time when they are highly stressed and grieving the loss of their child's health as well as dealing with other losses such as financial stability and the loss of time to spend with other children. Families of children who have life threatening conditions tend to be younger and have fewer resources. Their quality of life is significantly improved when the ill child's quality of life is enhanced.
- The grief associated with a child's death has devastating, long-term implications for the entire family. Siblings have unique needs during and after a child's death.

## What is the role of pediatric hospice palliative care during illness?

Pediatric hospice palliative care may be combined with therapies designed to reduce or cure illness, or it may be the only focus of care. Figure 1 shows the relative focus of care over time. The straight dashed line is used to distinguish therapies intended to modify disease from those that are intended to relieve suffering and/or improve the quality of life (i.e., hospice palliative care). The actual mix of concurrent therapies will vary for each child/family care situation based on their expectations and needs, goals of care, and treatment priorities.



**Figure 1: The Role of Pediatric Hospice Palliative Care**

Pediatric hospice palliative care should be available to children and families throughout their illness experience and beyond, whenever they have expectations and needs and are prepared to accept care. Pediatric hospice palliative care is appropriate for any pediatric patient and/or family living with a life-threatening condition due to any diagnosis. Caregivers work with other professionals, the child and family to provide pediatric hospice palliative care concurrently with active care. Although the child's care may focus more on palliation as the illness progresses, active treatment is part of hospice palliative care and both play an important role throughout a child's illness.

# Guiding Principles of Pediatric Hospice Palliative Care

Pediatric hospice palliative care is guided by the same values and principles as adult hospice palliative care. In addition, pediatric hospice palliative care reflects the following principles:

## 1. Child/Family Focused Care

The unit of care is the family, defined as the persons who provide physical, psychological, spiritual and social comfort to the child, and who are close in knowledge, care and affection - regardless of genetic relationships. Family members may include biological, marital, adoptive/custodial and family of choice ties/connections (including friends and pets). Children and families facing illness, dying and bereavement have inherent strengths. As part of the process of providing pediatric hospice palliative care, caregivers explore the child's/family's needs, hopes, beliefs, fears, expectations and strengths. All aspects of care are provided in a manner that is sensitive to the child's and family's personal, cultural and spiritual values, beliefs and practices, their developmental stage, and their preparedness to deal with the dying process. The child has the right to age-appropriate information about his/her illness, potential treatments and outcomes. The family and service providers have the right to be informed about the illness, potential treatments and outcomes, while respecting the child's right to confidentiality. Decisions are made by the child and family in collaboration with the caregivers and service providers. The care team respects the child's and family's choices.

## 2. The Value of the Therapeutic Relationship

A therapeutic relationship between health care professionals and the child/family is essential to the provision of pediatric hospice palliative care. Within this relationship, there is potential for healing in the midst of illness, death and bereavement.

## 3. Continuity of Care

Pediatric hospice palliative care strives to provide continuity of care among formal and informal caregivers, and across the continuum of illness, dying and bereavement.

## 4. Communication

Effective supportive pediatric hospice palliative care depends on the ability of the child/family and the palliative care team to communicate. Caregivers acknowledge and respect the child's/family's language preference. Interpreter services are used, whenever possible, to meet the care unit's communication needs.

## 5. Accessibility

Pediatric hospice palliative care is accessible to children and their families in a setting of their choice that is appropriate to their needs and resources. Pediatric hospice palliative care is available 24 hours a day, 7 days a week, and families have a contact person to help coordinate their care.

# Ethical Considerations in Pediatric Hospice Palliative Care

In their efforts to provide child/family-centred care, pediatric hospice palliative care providers will face a number of ethical issues including:

- **The child's ability to consent to treatment**  
Some provinces have established specific ages at which a child is able to consent to treatment. Others require that the child be capable of understanding the treatment being proposed, the benefits and risks, and alternatives, and make the decision without coercion. Emphasizing the competence or capacity of the child rather than age, allows children to participate in decisions regarding their care whenever possible and appropriate. However, not having a legal age of consent can cause parents and professionals to question how much responsibility or information a child should be given in his or her own treatment decisions.
- **The amount/type of information that should be shared with a child (i.e., truth telling)**  
Honest and sensitively communicated medical information helps patients and their families understand and deal with health issues and make informed choices about care options (Brinchmann, F.rde & Nortvedt; Hébert, 1996; Charlton, 1996; Hébert, Hoffmaster, Glass & Singer, 1999; Kuhl, 2002). When, what and how to disclose information to children must take into account the family's cultural or religious values and the child's capacity to understand. The significance of and approach used for truth-telling is strongly tied to an individual's or family's religious and cultural practices and values. A child also has the right to waive the option of receiving this information preferring instead that parents receive information on his or her behalf. If the health care team and the family cannot agree on the information to be shared with the child, the team should consult with an ethicist.
- **Family-focused decision making**  
Decisions regarding the medical care of children are generally made in a "triadic model" which involves the participation of the child (according to the child's ability and capacity), the child's parents and the health care team (Hardart, 2000; Harrison, Kenny, Sidarous & Rowell, 1999). In end of life care, decision making can be perceived by some families as profoundly burdensome if the primary responsibility for choosing among care options is placed on the parents at a time in which they are losing their child (Brinchmann, F.rde & Norvedt, 2002). Therefore, the role and participation of the health care team is crucial to imparting information, making recommendations and working collaboratively to reach a consensus on what is in the best interests of the child. With infants and young children, who have no significant decision-making capacity, parents and health care professionals should make decisions that are guided by the best interests of the child. With primary school children, who have some capacity, parents and professionals should provide age-appropriate information, seek the child's consent, take into consideration the child's dissent, and ensure the child's best interests are at the core of the decisions. With adolescents, who have greater capacity, care must be taken to determine whether a particular adolescent patient has the ability to understand and communicate relevant medical information, exercise independence, anticipate consequences or risks and demonstrate a stable set of values (Harrison et al., 1999). All decision making should be sensitive to the child's and family's cultural and religious values. It is important that professionals understand how the family's cultural or religious beliefs shape understanding of illness and death. If a conflict arises between the health care caregivers and the child's family about the child's participation in his or her own care, health care caregivers should enlist the assistance of a cultural interpreter, chaplain or ethicist. Pediatric hospice palliative care programs should also have an established process of conflict resolution.

- **Pain management**  
Health professionals providing pediatric hospice palliative care have an ethical duty to “pursue comfort aggressively” and minimize the child’s discomfort, suffering or pain (Wolfe, 2000). They have an ethical responsibility to provide adequate pain control and ensure that children are not under-treated because of ethical confusion, fear of the law or ignorance (Wolfe, 2000). The ethical obligations of beneficence, non-maleficence and the promotion of best interests of the patient should be used in guiding pain management decisions for children at end of life.
- **Decisions to forego potentially life-sustaining treatments or to withdraw life support**  
During the process of end of life care, health care professionals and parents will discuss foregoing life-sustaining treatment or withdrawing life support, and may participate in making these profoundly difficult decisions. To meet the requirements of non-maleficence (i.e., the duty to avoid harm or suffering), professionals must raise these issues sensitively (i.e., identify appropriate timing, and present their recommendations to parents in a sensitive and respectful way). These conversations require comfortable rooms that afford privacy, as well as sufficient time for the family to ask questions, discuss preferences, voice objections and express feelings. These decisions, like all other decisions in pediatric hospice palliative care, should be driven by the best interests of the child. It is important to consider the child’s values, beliefs and wishes as well as the options that are least likely to cause more suffering and/or prolong the dying process. It is also important to ensure that the self-interests of the parent(s) or over-riding familial interests do not dominate the decision-making.

# I. Child and Family Care

Child and family care consists of 9 types or domains of care, including:

- disease management
- physical care (including pain and symptom management)
- psychosocial care
- social care
- spiritual care
- developmental care
- practical care
- end of life, preparation for death care
- loss, grief and bereavement care

## Disease Management

### Principle

Children with cancer and their families have access to appropriate disease-modifying therapy.

### Norms of Practice

1. Determine advanced, progressive disease that will not respond to curative therapies and/or life-threatening comorbid conditions, and prognosis

Assessment: by oncologist	Plan/Actions:
<ul style="list-style-type: none"> <li>• Child's history of therapeutic interventions, their effectiveness</li> <li>• Laboratory tests, imaging, physical assessment</li> <li>• Consultation with colleagues; eg: tumor board, COG</li> <li>• Literature review</li> </ul>	<ul style="list-style-type: none"> <li>• Estimate prognosis based on:               <ul style="list-style-type: none"> <li>○ trajectory (IOM, pg 73-4) or natural course of the disease, including involvement of major organs</li> <li>○ child's history of response to treatment, adverse events, toxicities</li> <li>○ child's clinical condition</li> </ul> </li> </ul>

2. Decide on disease modifying treatment with child/family

Assessment: by oncologist and child/family	Plan/Actions:
<ul style="list-style-type: none"> <li>• Child's history of therapeutic interventions and their effectiveness, and adverse events</li> <li>• Risks and benefits of treatment options:               <ul style="list-style-type: none"> <li>○ Standard chemotherapy</li> <li>○ Clinical trials, including Phase I trials</li> <li>○ Local protocols</li> <li>○ Ongoing treatment for comorbid</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Review child's history with child/family</li> <li>• Determine intent of further disease-modifying therapy or treatment for comorbid conditions with child/family:               <ul style="list-style-type: none"> <li>○ Possibility (even remote) of cure/recovery</li> <li>○ Palliative intent: prolongation of life with good quality and relief of suffering</li> </ul> </li> </ul>

<b>Assessment:</b> by oncologist and child/family	<b>Plan/Actions:</b>
<ul style="list-style-type: none"> <li>○ conditions</li> <li>○ No treatment to control the disease-supportive care only; measure for comfort/control of symptoms</li> <li>○ CAM</li> <li>● Child/family's view of quality of life and suffering</li> <li>● Child/family's goals for treatment</li> <li>● How the disease/treatment is likely to affect the child/family physically, intellectually, emotionally</li> </ul>	<ul style="list-style-type: none"> <li>● Plan treatment based on assessment, prognosis, child/family wishes/goals, treatment available. Consider treatment based on prognosis of life expectancy: days to weeks, months to weeks, weeks to years <ul style="list-style-type: none"> <li>○ Consider options for delivery of care: <ul style="list-style-type: none"> <li>▪ Location: <ul style="list-style-type: none"> <li>~ BCCH: what they can expect from us</li> <li>~ Community based care: referrals, how we will work with community healthcare providers (HCP)</li> <li>~ Hospice services: Canuck Place</li> </ul> </li> <li>▪ Who will be delivering the care (professional caregivers)</li> <li>▪ Sources of support</li> <li>▪ Plan for emergency, ICU, DNR if applicable</li> </ul> </li> </ul> </li> <li>● Set reasonable goals for treatment/review with each interaction</li> <li>● Integrate palliative care to complement disease-modifying therapy</li> <li>● Review and reassess above regularly with child/family. Prepare to modify treatment plan as needed</li> <li>● Communicate plan with healthcare team: document in chart and update with each interaction</li> </ul>

3. Discuss the estimated prognosis and plan with the child/family.

<b>Assessment:</b> by any member of HC team	<b>Plan/Actions:</b>
	<ul style="list-style-type: none"> <li>● Primary oncologist is responsible for decisions re: disease modifying treatment or treatment for comorbid conditions</li> <li>● Consistent person(s) to communicate information. Limit number of people giving information.</li> <li>● Provide language/cultural interpreter as needed</li> <li>● Use appropriate language with children and families, including language related to dying and death, to minimize misconceptions and facilitate discussions to help prepare children and families for end of life</li> <li>● Plan initial meeting with child/family and appropriate HCP (eg: primary clinic nurse, social worker, CNS, etc) to discuss: <ul style="list-style-type: none"> <li>○ diagnosis/prognosis</li> </ul> </li> </ul>

Assessment: by any member of HC team	Plan/Actions:
	<ul style="list-style-type: none"> <li>○ evidence that cure is no longer possible</li> <li>○ likely course of the disease</li> <li>○ options for disease-modifying therapies</li> <li>○ the meaning and implications of the estimated prognosis</li> <li>○ respect the child's right to confidentiality</li> <li>● Review progress of disease/treatment with family asking them their assessment of: <ul style="list-style-type: none"> <li>○ progress since last seen</li> <li>○ what is observed , eg: inc or dec in symptoms, etc: facts</li> <li>○ where we are now</li> <li>○ where we are going</li> <li>○ child/family's wishes and goals</li> </ul> </li> <li>● Offer written documentation of interactions as desired by child/family</li> <li>● Document in chart and update with each interaction</li> <li>● Review current treatment plan with the child/family and modify as needed. Assure the child/family that care and treatment continue even when the goals of treatment change</li> </ul>

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- IOM, When Children Die: Improving palliative and end-of-life care for children and their families, 2003. pg.9 +
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# Physical Care *(including pain and symptom management)*

## Principles

Symptoms include emotional and spiritual distress, such as boredom, depression, loneliness and sadness, as well as physical suffering. Effective symptom management addresses physical, cognitive, emotional and spiritual symptoms in order to ease the “total” pain and suffering a child and family experiences. (this section addresses only physical symptoms)

Pain and other symptoms are managed aggressively to achieve the greatest possible relief for the child and family.

Age, developmental level, illness trajectory, cultural and language issues, coping skills, and previous experience with pain/symptoms can affect a child’s perception and experience of pain and other symptoms.

The child and family may choose to use alternative and complementary therapies (CAM) for pain and symptom management. HCP’s work within an ethical framework to provide holistic care that is based on best practices and the wishes of the child and family.

Access to HCP’s with expertise in pediatric oncology hospice palliative care is available 24 hours a day, 7 days a week.

## Norms of Practice

HCP’s assess specific patient and family needs related to pain and symptom management. Assessment is ongoing and based on age appropriate and valid assessment tools.

The plan of care addresses the physical expectations and needs of the child and family, and includes an effective pain and symptom management plan as well as plans for appropriate management of potential pharmacological side effects and complications.

The child should be assessed for signs and symptoms, which include, but are not limited to:

- cardio-respiratory (e.g., shortness of breath, respiratory distress/failure, cough, edema, hiccups)
- gastrointestinal (e.g., nausea, vomiting, constipation, bowel obstruction, diarrhea, odor)
- fatigue
- hematological (bleeding, anemia)
- skin (breakdown, pruritis, odor)
- nutritional (anorexia, cachexia)
- fever/infection
- mobility (muscle weakness, walking, gait, body alignment and contractures)
- neurological (e.g., seizures, cord compression, level of consciousness, mobility, incontinence, weakness, muscle spasms, swallowing, speech).
- psychological that affect physical suffering (depression, sleeplessness, anxiety, agitation, confusion/dementia)
- metabolic (electrolyte imbalances, SIADH, DI, hormone problems)
- tumor breakdown and erosion

HCP's discuss the child's and family's wishes regarding supportive care, which include but are not limited to:

- transfusions
- antibiotics and other medications, ie, steroids
- fluids and electrolytes
- blood work
- nutrition support
- resuscitation support
- hospital/clinic visits
- physical exam
- imaging
- further disease management, ie: chemotherapy, radiation therapy, surgery
- comfort measures

The pediatric oncology palliative care team uses physical and occupational therapy resources to optimize the child's function and mobility.

HCP's continuously adjust the child's fluid and nutritional intake to accommodate changes in the child's ability to swallow and retain fluids in the intravascular space as well as changes in renal and hepatic function and other quality of life issues.

The child's sensory experiences of sight, hearing, touch, taste and smell are optimized.

The most effective, least invasive, evidence-based pain and symptom care interventions are used, based on the child's needs, to provide comfort, connection and communication between the ill child and his or her family, friends/peers and community.

Non-pharmacological management and distraction techniques (e.g., music, art, books, journaling, guided imagery, clown therapy and play, hypnosis) are offered when appropriate, based on the assessment of the child's needs and interests.

Families are encouraged to discuss CAM with their caregivers. Caregivers will support the family's wishes within the context of ethical practice. Caregivers will make every effort to address side effects and provide comfort measures.

Caregivers consult with specialists in pain and hospice palliative care as needed to optimize pain and symptom management.

All interventions and their effectiveness are documented and the data used to inform care decisions.

Team members are involved in evaluating and documenting symptom management strategies and interventions.

Caregivers receive ongoing education/training in pain and symptom assessment and management, including adjusting/evaluating symptom management strategies.

# Psychosocial Care

## Principles

Pediatric hospice palliative care addresses the psychological well-being of the child and family, and takes into account the emotional, cognitive, and behavioural impact of the illness, and each family member's personality, coping strategies, and past experiences.

Hospice palliative care for children and their families depends on a holistic collaborative approach to spiritual, social, cultural, and psychological care.

## Norms of Practice

The child/family's emotional well-being is assessed. Caregivers ask the child and family about their specific thoughts, feelings, hopes, wishes and fears, and develop an awareness of the child's and family's psychological expectations and needs, and their personalities, emotional status, coping strategies, past experiences, and any pre-existing psychological conditions. Consultation and collaboration of the interdisciplinary team are necessary.

The plan of care addresses psychosocial needs and provides psychological support that promotes the child's and family's coping skills and positive adjustment, supports their achievement of personal goals, and optimizes their quality of life.

Feelings of anxiety, depression, anger, anticipatory grief, helplessness, and hopelessness are examined directly and addressed.

The child's cognitive function is preserved and developed.

The child's sense of independence and control are supported.

Caregivers support the child's and family's desire for intimacy, privacy and connection.

Caregivers support and respect a family's need to maintain hope for a cure and/or miracle throughout the entire course of their palliative care.

Caregivers support and respect a family's need to maintain hope for a cure and/or miracle throughout the entire course of their palliative care.

Caregivers address the child's fears, sense of being a burden and desire to protect their family, as well as the child's and family's feelings of grief (e.g. loneliness, unresolved guilt, anger, hopelessness).

Caregivers strive to ensure that the child and family have opportunities for personal growth, joy and celebration. The care plan includes occasion for education, play, and interaction with family and peers, as well as other developmentally appropriate activities. Legacy building may be important (Hockley, 2000).

The child's and family's dignity is preserved

Caregivers provide psychological care for the family during the bereavement process. Families are offered referrals to community resources that provide bereavement support.

<b>DISCIPLINE</b>	<b>SUPPORTS PROVIDED</b>	<b>EXAMPLES</b>
<b>Social work</b>	<ul style="list-style-type: none"> <li>• Funding support</li> <li>• Support for management of care at home</li> <li>• Social support</li> <li>• Grief and bereavement support</li> <li>• Assist through changes of treatment focus through support and education</li> </ul>	<ul style="list-style-type: none"> <li>• At home program referral</li> <li>• B.C. Palliative care benefits program referral</li> <li>• Counseling</li> </ul>
<b>Psychology &amp; Counseling</b>	<ul style="list-style-type: none"> <li>• Explore feelings and emotions</li> <li>• Provide with coping strategies</li> <li>• Provide with communication strategies</li> <li>• Explore concepts of death and dying according to developmental stage</li> <li>• Provide grief and bereavement support</li> <li>• Assist with changes in treatment focus through support</li> </ul>	<ul style="list-style-type: none"> <li>• Work with parents on how to talk with their children about death and dying</li> <li>• Examine family beliefs about spirituality and death and dying</li> <li>• Examine/explore family coping strategies and strengths</li> </ul>
<b>Psychiatry</b>	<ul style="list-style-type: none"> <li>• Assessment and management of more complex psychiatric needs</li> </ul>	<ul style="list-style-type: none"> <li>• Possible need for medication</li> </ul>
<b>Child Life</b>	<ul style="list-style-type: none"> <li>• Medical play</li> <li>• Coping strategies</li> <li>• Support in “making memories”</li> <li>• Explore concepts of death and dying according to child’s developmental stage and willingness</li> </ul>	<ul style="list-style-type: none"> <li>• Strategies for coping with pain, using imagery, music, and other non-invasive strategies</li> <li>• Making hand/foot molds, taking pictures, scrap-booking</li> </ul>
<b>Nursing</b>	<ul style="list-style-type: none"> <li>• Coordination of caregivers</li> <li>• Include psychosocial needs in care plan of child</li> <li>• Explore emotional well-being and identify and access support</li> <li>• Provide grief and bereavement support</li> <li>• Assist with changes in treatment focus through education and support</li> </ul>	<ul style="list-style-type: none"> <li>• Coordination of OT/PT in community if needed</li> <li>• Referral to Nursing Support Services</li> <li>• Referral to local palliative care team or Canuck Place</li> <li>• Education of family about disease progression and end of life care</li> </ul>
<b>Spiritual care</b>	<ul style="list-style-type: none"> <li>• Assess and support spiritual needs</li> <li>• Explore concepts and beliefs of death and dying</li> </ul>	<ul style="list-style-type: none"> <li>• Provide opportunity for expression of spiritual needs</li> <li>• May assist with funeral arrangements</li> </ul>
<b>Medical Team</b>	<ul style="list-style-type: none"> <li>• Provide information and respond to questions</li> <li>• Assist with communication of difficult information to the child/patient</li> <li>• Consider family beliefs/values and cultural implications for making care decisions</li> </ul>	<ul style="list-style-type: none"> <li>• Practitioner may tell the child/patient that there is no longer treatment available to make them better, rather than the parents doing so.</li> </ul>

# Social Care

## Principle

Pediatric hospice palliative care is offered in a social context, and is based on an understanding of the child's and family's place in a network of extended family, friends, and community and the implications for interaction, communication, and decision-making with and within the family.

Pediatric hospice palliative care takes into account relationship and communication issues within the extended family, the health-care setting, and the family's communities.

Pediatric hospice palliative care is culturally sensitive, and takes into account the beliefs, values, actions, customs, and the unique health care needs the child and family.

## Norms of Practice

Caregivers develop an awareness of the family's social context through conversations with the child and family. Caregivers ask the child and family about family relationships, available support systems, and resources, and develop an awareness of the family's social context.

The plan of care addresses the social expectations and needs of the child and family, and strives to support the importance, meaning and role of each person involved with the child.

The child and family are supported in reconciling relationships. Caregivers appreciate the intense physical, emotional, social and economic demands placed on a family caring for a child at home, or during prolonged and/or repeated hospitalizations. The family's ability to meet these demands with existing resources is assessed. (Hockley, 2000)

Caregivers educate and support the child's and family's network of extended family, friends and community as appropriate. Caregivers strive to create/maintain an environment that is safe and comforting, provides ample opportunity for communication, intimacy and privacy, supports family relationships, and supports the family/caregiver therapeutic relationship.

Caregivers are aware of the potential impact of cultural diversity on interaction, communication, and decision-making and have access to cultural profiles that help them understand child and family preferences (e.g., in some cultures truth-telling is a means of empowering the patient, while other cultures perceive truth-telling as robbing the individual of hope) (Candib et al, 2002).

Caregivers ask the child and family about their own unique beliefs, values, and practices, and attempt to harmonize the beliefs and practices of the health-care system with those of the child and family. Consultation is available to family and caregivers when there is a conflict based on cultural values and beliefs.

Cultural interpreters made available to the families should they so wish (multicultural services at C&W and UBC)

Pamphlets on truth-telling and talking with family and friends and siblings available for all families. 'Griefworks network' – on-line resource for families and health care providers

# Spiritual Care

## Principles

Pediatric hospice palliative care is care of the spirit. The child's and family's sense of hope and self-worth, sense of meaning and purpose, and their interconnectedness with others is vital in providing spiritual care.

Spiritual concerns are as integral to a patient and family as religious ones. For the child or family, their spirituality may be the way they express their inner resources, or the central philosophy that guides and gives meaning to their lives.

Individual family members may differ in their adherence to religious or spiritual practices.

## Norms of Practice

Caregivers ask about the child's and family's beliefs and values, and determine what distinguishes spiritual from religious practice for the child and family

Caregivers identify, acknowledge and respect the things that are meaningful and valuable to the child and family.

The plan of care addresses the child's and family's spiritual expectations and needs.

Caregivers facilitate meaningful and valuable experiences for the child and family

Caregivers address the child's and family's existential questions and other spiritual issues (e.g. the child dying before the parent).

Caregivers help the child and family access appropriate spiritual and/or religious resources, preferably those already known to the family. Where possible, personal spiritual advisors become part of the child's care team

Staff has access to information about religious traditions

# Developmental Care

## Principles

Children and adolescents are in a process of physical, emotional, cognitive and spiritual development. Depending on their developmental stage, they have different skills and different emotional, physical and development issues/needs.

Children and adolescents communicate differently, and their understanding of illness, death and dying depends on their stage of development. Their concepts of illness and dying continue to evolve over time, and develop in association with life and illness experience.

School is an essential integral part of children's lives. Education opportunities are incorporated into their dying journey.

In families experiencing the death of a child, the child and his/her siblings may exhibit behaviours above or below the norms associated with their age, stage and illness/condition. Pediatric hospice palliative care provides care and support that is adapted to the children's developmental needs.

## Norms of Practice

The child and his/her siblings' developmental needs are assessed and addressed in the plan of care. Plan made to support joy for child and siblings.

Caregivers adapt care to support the children's progress toward developmental norms.

Parents receive guidance and education to enhance the skills required to parent a child with a life limiting condition.

Caregivers provide guidance and support for the child and family to facilitate their development.

Schooling is arranged to meet the needs of the child and/or siblings, wherever the child is living.

Home tutor through the school board can be arranged.

Hospital school available for child and siblings.

Visits to local school by HCP can be arranged. These are developmentally appropriate presentation and allows for adequate questions and answers.

Caregivers identify a variety of verbal, nonverbal, and/or symbolic methods appropriate to the child's developmental level and communication style if required to communicate with the child.

Sibling needs are met by group support, individual consultation or referral to psychology or psychiatry or regional mental health program.

# Practical Care

## Principle

Practical care and support is an integral part of pediatric oncology hospice palliative care. The child's and family's practical needs must be met to ensure quality of life.

## Norms of Practice

The child's and family's goals for quality of life are identified and communicated to the interdisciplinary team.(See Disease Management and Physical Care Norms)

The plan of care identifies the community and other resources required to address the child's and family's practical expectations and needs.

The family's need for assistance with physical care of the child is addressed.

The family's equipment and supply needs are addressed.

The family's need for financial support for the child's care is addressed.

The family's need for support, relief and respite is addressed. Appropriate referrals may include:

- programs that provide financial support, ie: At-Home Program, Brain Injury Program
- home nursing coordination, ie: home care nurses, palliative nurses, Nursing Support Services
- respite services, i.e, Nursing Support Services, homemaking
- hospices, ie: Canuck Place, community-based hospices
- community support groups, ie, Compassionate Friends

Informal caregivers are trained and supported by the interdisciplinary team.

# End of Life/Preparation for Death Care

## Principles

Preparation for death is an integral part of pediatric hospice palliative care.

## Norms of Practice

The plan of care helps children and families prepare for and manage the child's end of life and death.

Symptoms and physiological changes associated with the last hours of living and death are anticipated, discussed with the child and family, and managed effectively.

Decisions about advance directives are clearly articulated and reviewed with the family, including conversations and decisions regarding autopsy, organ and tissue donation.

The child and family are encouraged to prepare for death by participating in rites and rituals that are important to the family, and/or in life closure, gift giving, legacies and other meaningful activities.

Caregivers help the child and family plan a funeral, memorial or other meaningful services/celebrations of life.

The family is offered anticipatory grief support as well as grief and bereavement materials to help prepare for a child's death.

"Making Hard Decisions About Care" package, BC Children's Hospital and Canuck Place

The child's death is determined (i.e. pronounced), documented and communicated in accordance with regulation, policies and laws.

The child's body is handled with respect and dignity in accordance with the wishes of the child and family.

# Loss, Grief, Bereavement Care

## Principles

The relationships that families develop with the child's caregivers and the family's experience of illness have a profound impact on their subsequent experience of death and bereavement.

Loss, grief and bereavement care is delivered in the context of wellness not pathology. Pediatric hospice palliative care focuses on providing support (not treatment) for people experiencing grief and bereavement.

Loss, grief and bereavement care includes: a compassionate acknowledgement of the child's death, emotional and practical support, an assessment of family coping, and help accessing other community resources.

While most people experiencing grief do not require treatment, those experiencing complicated grief or bereavement (i.e. a more intense response to loss) may require counseling and treatment.

Pediatric hospice palliative care supports the family in creating/performing rituals that give unique personal meaning to the experience of illness, death and bereavement and respect the family's culture and preferences.

## Norms of Practice

Families of children with progressive life-threatening illnesses have access to the services of hospital and community professionals with specialized expertise in grief and bereavement care. These professionals may become involved with a family at any point in their illness experience, depending on the family's preference and need.

Family members are offered bereavement care following the death of a child.

Caregivers support the patient and family in their grieving process by, for example, helping with planning and preparation for funeral services, burial ceremonies and/or other culturally appropriate rituals.

Caregivers offer families a variety of supports and resources to address the physical, emotional and spiritual needs associated with loss and grief including, but not limited to:

- de-briefing sessions
- help planning/preparing for funeral services, burial ceremonies and/or other culturally appropriate rituals
- memorial services
- bereavement kits
- referrals to community bereavement services
- support accessing grief and bereavement resources in hospital, home and community settings (e.g. support groups, peer support and trained volunteers).

Community cultural leaders may be asked to participate in loss, grief and bereavement care.

The responsibility for bereavement care may be assumed by one or more member(s) of the care team who have developed a relationship with the family.

Families are offered ongoing bereavement support/contact for a minimum of one year. Caregivers contact families by phone or letter two to four weeks after the child's death to acknowledge the death, offer condolences, and provide support and information.

Team members have access to guidelines for supportive follow up contact.

Individuals with complicated grief and trauma are offered access to grief counseling.

Caregivers receive education and support to help them identify complicated grief reactions and provide support in this challenging work.

Caregivers working with children and families who face progressive, life-threatening illness are offered grief and bereavement support.

## II. The Process of Providing Care

The process of providing care consists of 6 steps or functions:

- assessment
- information sharing
- decision making
- therapeutic interventions
- care delivery (including interdisciplinary team care and continuity of care)
- evaluation of care

### Assessment

#### Principles

Assessment guides the clinician in understanding the child's experience of his or her illness/condition.

Assessment is comprehensive and timely so clinicians have adequate information to guide the plan of care.

The assessment is supported by appropriate documentation.

#### Norms of Practice

Assessors gather appropriate information about the child's and family's history, respecting their privacy and using reliable assessment techniques and tools.

History taking and physical examination are completed on admission and at regular intervals to ensure caregivers have adequate information to guide the plan of care

The initial assessment includes:

- identifying and prioritizing issues (expectations and needs) important to the child, family, and caregivers
- assessing the child's and family's developmental level, personal, cultural and spiritual values, beliefs and practices
- assessing family structure, life/environmental context, family strengths, and family support

The child's and family's perspectives are incorporated into the assessments of new and ongoing issues.

Based on the assessment, caregivers suggest laboratory tests and diagnostic studies when they have the potential to benefit the child without undue risk or burden.

# Information Sharing

## Principles

The child has the right to be informed about his or her condition/illness, available treatment options, and their potential benefits, risks and burdens and to be invited to participate in decision making (Child Act).

Parents/substitute decision makers, with the guidance of professionals, determine how, when, and what information is shared with the child, taking into account the specific child, family situation characteristics, such as temperament, cognitive abilities, developmental level, cultural beliefs and values.

Parents/substitute decision makers are entitled to information about the child's disease or condition, available treatment options, and their potential benefits, risks and burdens.

Effective communication and information sharing with the child and family gives caregivers the information they need to provide effective care.

## Norms of Practice

Before sharing information, caregivers establish limits of privacy as defined by the child and family, and establish what the child and family already know and what they would like to know, in accordance with the ethical principle of truth telling.

Information is shared in a language, manner and setting understandable and acceptable to the child and family.

Interpretation is provided by skilled medical interpreters who understand the meaning of medical concepts and terminology, not family members or anyone who simply "speaks the language".

Caregivers explore the expressive functioning/communication styles within the family, how family members normally share information, and any beliefs that may keep them from speaking with one another about difficult emotions/fears/worries.

Accurate information is shared in a timely way and when the recipients are ready to receive it.

Caregivers regularly assess the child's and family's understanding and reactions to information, and their desire for additional information.

When the family and caregivers disagree about information to be shared with the child, they use the principles of negotiation and conflict resolution to reach agreement. If they cannot reach agreement, they have access to the services of a child advocate or ethicist.

# Decision - Making

## Principles

The child and family have the right to make informed decisions, determine goals for care, and establish treatment priorities for present and future care.

The child who has the capacity to make decisions gives consent to any treatment. At any time, the child may refuse any treatment or ask to have any treatment withdrawn. The care team respects the child's choices.

When a child lacks the capacity to make decisions, approaches to decision-making are guided by ethical and legal principles of substitute decision-making.

Even when a child is found to be incapable of decision making, he or she is still encouraged to contribute to the plan of care.

## Norms of Practice

The decision-making process respects the confidentiality of the family, and decisions made by families are confidential.

Caregivers regularly assess the child's and family's goals for care, the appropriateness of therapeutic interventions in light of those goals, the potential therapeutic burden of each intervention, and the child's decision-making capacity. This information is reviewed by the child, family and caregivers, and the plan of care adjusted accordingly.

Caregivers communicate the meaning and implications of the estimated prognosis with the child and family, respecting the child's right to confidentiality.

Children and families are informed about appropriate therapeutic options available to address their expectations and needs.

Children and families have access to assistance, without coercion or prejudice, in selecting treatment priorities and settings of care from appropriate options.

Requests to withhold or withdraw therapies are discussed openly. Within their capacity to make decisions, children are given the opportunity to discuss advance directives.

Requests for care that appears to have no benefit to the child and family, and the factors underlying those requests, are discussed openly.

Requests for hastened death (i.e., euthanasia or assisted suicide), and the factors underlying those requests, are addressed in a timely way.

When there is conflict between the caregiver, the family, and/or the child, all options are discussed openly and consensus is reached which reflects the best interests of the child. Reaching consensus may require mediation.

# Therapeutic Interventions

## Principles

Medications, therapies, equipment and supplies consistent with the goals of care and treatment priorities of the child and family are used appropriately, safely, and in a manner that optimizes their potential benefit and minimizes their risks and burden.

## Norms of Practice

All therapeutic interventions are provided in a manner that:

- is safe and secure
- consistent with preferred practice guidelines
- minimizes the risks of adverse effects or medical interactions and burdens for the child and family

Caregivers establish an effective process for:

- Handling hazardous materials, including biological substances
- Disposing of controlled medications and biological wastes

Equipment and supplies are used in a manner consistent with manufacturers'/suppliers' instructions.

All members of the interdisciplinary team encourage or participate in therapeutic interventions that are legal.

The child, family and caregivers are educated about the appropriate use of medications, therapies, equipment and supplies.

Caregivers repeatedly check and reinforce the child's, family's and caregiver's understanding of the appropriate use of medications, therapies, equipment and supplies.

Incidents and adverse events are reported and recorded in a timely way.

# Care Delivery

## Principles

Members of the Oncology/Hematology/BMT Program strive to help children and families have equal and timely access to pediatric hospice palliative care services when they need them and are prepared to accept them, wherever they live, in whatever setting – regardless of diagnosis, prognosis, geographic location, age, gender, spiritual/cultural values, or financial circumstances.

Pediatric hospice palliative services are provided without discrimination or prejudice, in a manner acceptable to the child and family.

Pediatric hospice palliative care is provided by an interdisciplinary team of competent and compassionate caregivers who work collaboratively with the child and family. The team includes, but is not limited to, physicians, nurses, social workers, psychologists, chaplains, child life specialists, and trained volunteers.

Communication with the child, family and other members of the child's community is ethical, open and honest, and respectful of the family's wishes.

Pediatric oncology hospice palliative care provides continuity of care from diagnosis to bereavement, and across care settings.

## Norms of Practice

Care is provided by an interdisciplinary team of caregivers with the appropriate assessment, planning, care giving and communication skills.

Team members support therapeutic relationships that family members have established. The child's primary care and specialist caregivers remain involved in the child's care, if the child and family wish them to do so. Members of the Oncology/Hematology/BMT Program remain involved with the child/family as needed in whatever capacity is best for the child, family, community based caregivers (ie: as temporary primary caregivers, consultants, supports)

Essential services are available 24 hours per day, 7 days a week. The child, family and all team members know the contact information for after hours and/or urgent care.

Pediatric hospice palliative care consultation and/or services are available regardless of geographic location.

The interdisciplinary team creates a network of hospital and community supports (e.g., ethicists, physiotherapists, occupational and speech therapists, dieticians, art and music therapists, complementary health professionals) to address the child's and family's needs. Expert consultation is sought in a timely manner.

The team develops and negotiates an individualized, flexible plan of care with the child and family.

The team works with the child and family to develop a collaborative, culturally sensitive decision-making process. All decisions are implemented and documented in a timely manner.

The core interdisciplinary team meets and consults regularly with the child and family. The interdisciplinary team reviews the plan of care regularly and revises it as necessary.

The team establishes effective ways to communicate and share appropriate information with the child, family and team members, which respect the family's confidentiality and privacy.

Care is provided in collaboration with the child and family

Care is provided in a language and manner that are understandable and acceptable to the child and family.

There is no evidence of discrimination or prejudice by caregivers.

Caregivers respect the personal boundaries necessary to achieve effective therapeutic relationships

Caregivers have the resources they need to deliver the plan of care.

Care is coordinated by designated caregiver(s) in collaboration with the child and family. There is continuity of the plan of care across all settings of care, and among all caregivers and programs/services involved with the child and family.

There is consistency and continuity of caregivers

Agency policies and procedures guide clinical practices

Available programs and services collaborate to address the pediatric hospice palliative care needs of a community

# Evaluation of Care

## Principles

Pediatric hospice palliative care is a continual process of assessing, evaluating and adjusting the services provided to meet the child's and family's needs and reduce their suffering. Caregivers continually strive to improve the quality and effectiveness of hospice palliative care.

## Norms of Practice

The child's and family's overall understanding, satisfaction, sense of complexity, level of stress, concerns, questions and desire for additional information is assessed during each therapeutic encounter.

During each therapeutic encounter, the caregiver assesses and reinforces the child, family's and informal caregiver's understanding of:

- the situation
- the plan of care
- the appropriate use of medications, therapies, equipment and supplies.

Assessments are communicated so that all members of the team are informed of the child and family's current information. Caregivers are sensitive to the needs of the family and take care not to repeat assessments and therapeutic interactions if it can be avoided. (eg: only 1 or 2 members of the team should be responsible for discussing DNR options)

During each therapeutic encounter, the HCP assesses the child's, family's, and caregivers':

- satisfaction with the process of providing care and their overall situation
- perception of the complexity of the situation
- perception of the level of stress
- ability to provide and participate in the plan of care.

Caregivers systematically use the results of their evaluations to revise the plan of care and improve care for the child and family. This is communicated to all team members.

# III. Program Support Functions

Program support functions include:

- quality management
- evaluation
- research
- education
- caregiver support/worklife

## Quality Management

### Principles

Ongoing evaluation improves the quality of pediatric hospice palliative care services.

The goal of evaluation and quality management is to:

- assess the effectiveness of the service in achieving its goal (see box) and providing quality care
- ensure the needs of the children and families are understood and met
- ensure the care and services provided are safe, effective and efficient
- continually improve the care and services provided.

The team meets the unique needs of dying children and their families by:

- Helping them manage their pain and symptoms
- Helping children and families plan for death
- Addressing children's and families' psychosocial and spiritual needs
- Helping children and families link with support groups and hospice caregivers
- Respecting the child's and families' cultural beliefs about dying

CCHSA (2004)

### Norms of Practice

The pediatric hospice palliative care program has policies and procedures based on accepted evidence-based norms of practice for hospice palliative care and for grief and bereavement support as well as standards of professional conduct.

Accreditation standards related to the unique needs of pediatric oncology palliative patients are addressed (Achieving Improved Measurement, 2004)

The program has a systematic approach to evaluation (e.g., quality review cycles) that includes documentation, data collection, and a regular review process.

The Oncology Program Quality of Care committee reviews quality management, policies and procedures, and guidelines of practice.

Performance improvement evaluation includes: routine measures of clinical outcomes, adverse events, medication and other therapeutic errors, resource utilization, child and family satisfaction, and complaint resolution as per the Children's Oncology Group standards.

Clinical outcomes are identified and measured using sound instruments.

Families are aware of how to voice complaints or grievances, and are assured they will continue to receive quality service.

Caregivers obtain ongoing feedback from the families and children they serve, and work to integrate this information into their practices.

# Research

## Principles

The development, dissemination and integration of new knowledge is essential to advance quality pediatric hospice palliative care.

Children, families and others who consent to participate in research are treated sensitively and ethically.

Research priorities are informed by the Canadian Agenda for Research in Palliative Care, (CHPCA, 1999), the Canadian Institute of Health Research (CIHR), the Institute of Medicine (Field M, Berhman R, 2003), Children's Oncology Group, and other related research bodies and pediatric/adult health and hospice palliative care leaders (see Appendix G for a list of potential research priorities and questions).

## Norms of Practice

Capacity building opportunities, such as interdisciplinary research fellowships, are available to help develop new investigators.

Knowledge is disseminated and integrated into clinical practice and models of service delivery.

Knowledge is disseminated using appropriate methods of knowledge transfer and knowledge translation.

Knowledge is disseminated in national and international forums (e.g., peer reviewed journals, conferences, relevant websites).

The program encourages opportunities for cross-disciplinary and multi-site research partnerships.

Qualitative research methods are recognized as meaningful in understanding the experience of living with a life threatening condition, dying, death, and grief.

Research is conducted within the guidelines of the relevant scientific and ethics research boards and guided by national policies for ethical conduct.

Phase I and II studies are offered as described in the "Disease Management" section.

# Education

## Principles

Pediatric oncology hospice palliative care providers have specialized knowledge/expertise in the delivery of hospice palliative care to children with cancer and their families. This knowledge is continually evolving.

Health care professionals in both academic centres and the community strive to engage in a continuing dialogue about the relief of physical, cognitive, emotional and spiritual suffering in the midst of pediatric progressive, life-threatening illness, and about the societal value of grief and bereavement support, particularly for siblings, classmates, and friends. This sharing of information and practice experience enhances the quality of hospice palliative care available to children, families and communities.

## Norms of Practice

Members of the pediatric oncology program are encouraged to seek opportunities for life long learning and the development of additional academic and practice expertise.

Caregivers have access to various educational initiatives, including adult hospice education, palliative care conference presentations, palliative care rounds with national pediatric hospice palliative care experts (teleconference), informal discussions with hospital and community health care professionals, and academic coursework.

# Caregiver Support/Worklife

## Principles

Formal and informal caregivers' physical, psychological, and spiritual well-being is integral to the provision of pediatric hospice palliative care.

## Norms of Practice

Employees and volunteers are satisfied with the support they receive from the program.

Ongoing programs are in place to address employee issues and improve worklife satisfaction. (ie: EAP program)

The program works to identify and minimize occupational risks and stresses.

Caregivers have access to ongoing support, including grief and bereavement support. (eg: debriefings as needed, Critical Incident Stress Management program)

Caregivers continually reflect on their own comfort and ability to enter into difficult conversations with children and families. They support one another and are willing to ask for help when feeling unsure/uncomfortable.

## **Additional Guidelines**

C&W Administration Manual:

AE0300 – Guidelines for “Do Not Resuscitate” (DNR) Decision-Making for Children

AP0540 – Informed Consent: Autopsy (Post-Mortem Examination)

C&W Medical Staff Rules:

Article 3.0: Responsibility for Patient Care – 3.11 Pronouncement of Death, Autopsy and Pathology

Nursing Policy & Procedure Manual:

NP005 – Post Mortem Care