

# Caring for Children with Life Threatening Illnesses



## A Guide to Pandemic Planning for Paediatric Palliative Care

2015 Edition

# **A Guide to Pandemic Planning for Paediatric Palliative Care**

November 2015 Edition

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For online access to this Guide please visit:

Canadian Hospice Palliative Care Association (CHPCA) at: [www.chpca.net](http://www.chpca.net)

Canadian Network of Palliative Care for Children (CNPC) at: [www.cnpsc.ca](http://www.cnpsc.ca)

Emergency Nurses Association of Ontario (ENAO) at: [www.enao.me/](http://www.enao.me/)

Infection Prevention and Control Canada (IPAC) at: [www.ipac-canada.org](http://www.ipac-canada.org)

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## Summary of the Paediatric Palliative Care Pandemic Planning Guide

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- ❖ The Paediatric Palliative Care Pandemic Planning Guide offers a planning framework for addressing the unique needs of children requiring hospitalization due to pre-existing life threatening illnesses as well as children who become fatally ill as a result of a pandemic.
- ❖ The Paediatric Palliative Care Pandemic Planning Guide is based on the following palliative care principles: family-centered care, effective pain and symptom management, quality and dignity at end-of-life, honest communication, shared decision making of treatment goals, and the provision of grief and bereavement support.
- ❖ Key activities focus on implementing transparent and proactive communication strategies, adapting institutional infection prevention and control practices and developing family access policies that promote high quality palliation, end-of-life and grief care.
- ❖ The Paediatric Palliative Care Pandemic Planning Guide is meant to be continuously developed within and among partnerships between pediatric hospitals, hospices, community services, local organizations and government as new pandemic learnings evolve.

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## BACKGROUND

Governments and health care systems around the world have engaged in varying levels of pandemic planning activities. The World Health Organization suggests that subsequent pandemics are expected and possibly imminent and that most countries around the world are “ill-prepared” for such an inevitability (World Health Organization, 2004). Research following the 2003 SARS outbreak reported enormous health, social and economic disruptions despite the relatively low rate of infection and mortality (World Health Organization, 2003). Therefore, it is crucial for health care settings to specifically develop mechanisms to minimize serious illness and overall deaths, provide optimal care to children with pre-existing health care needs, ensure the safety of health care providers, maximize personal and social resilience, and reduce family and societal disruption.

At the time of this writing (2015), outbreaks such as MERS-CoV (Middle East Respiratory Syndrome-Coronavirus), H5N1 avian influenza, Ebola, and Enterovirus D68 illustrate the importance of careful pandemic preparedness. And yet it is well documented that paediatric pandemic preparedness has received inadequate attention across Canada (Nicholas, 2010). The care of children during a pandemic has been reported to result in significant challenges for paediatric hospitals (Ratnapalan, 2013) including the provision of family-centered care to children and their families (Koller, 2006).

Pandemic planning requires multi-phase specific planning including multi-disciplinary, interagency/multi-sectoral planning groups, ongoing communication, and updates and post pandemic reviews. Paediatric populations and subpopulations such as children with life-threatening illnesses will have unique needs that require particular attention within a pediatric hospital’s pandemic plan.

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## RATIONALE: THE IMPORTANCE OF PANDEMIC PLANNING IN PAEDIATRIC PALLIATIVE CARE

Paediatric palliative care is both a philosophy and an organized method for delivering competent, compassionate, and consistent care to children with chronic and/or complex life-threatening conditions and their families (Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice, Canadian Hospice Palliative Care Association, 2006). Care focuses on enhancing quality of life, minimizing suffering, optimizing function, and providing opportunities for personal, family and spiritual growth. Lessons learned from the SARS outbreak in Canada indicated that paediatric facilities world-wide found it challenging to balance infection control policies and practices while maintaining family-centered care (Koller et al., 2006; Beck et al., 2004; Chan et al., 2006; Chan et al., 2007, Nicholas et al, 2008).

Our clinical and research experience suggested that SARS resulted in significant hardships (including family/child separation, communication challenges and disruptions to family-centered care palliative care practices) for inpatient children dying of life-threatening conditions and their families (Beaune, Nicholas, Hockey, 2012). Maintaining excellent family-centered palliative care within a pandemic outbreak therefore requires thoughtful planning.

This document is meant to support health care settings in providing palliative and bereavement care services when specialist services and resources are scarce, when children require palliative and end-of-life care and when the hospital is overwhelmed with numbers of children requiring symptom management and end-of-life and bereavement care.

This document was developed to ensure and uphold the rights and unique needs of two paediatric populations during a time of a pandemic:

1. Children with chronic, complex and/or life threatening health conditions who are receiving palliative care and/or who would benefit from palliative care, and
2. Children who become rapidly and terminally ill as a result of a pandemic.

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## **POTENTIAL IMPACT OF PANDEMIC ON HOSPITAL BASED PALLIATIVE AND BEREAVEMENT CARE SERVICES**

- Increased number of dying children requiring hospitalization
- Decreased number of staff due to illness and/or re-deployment
- Increased demand for community health care
- Increased demand for emergency or respite care for children with life threatening conditions at home if parents/caregivers become unwell
- Change/restrictions to palliative and bereavement care practices that may impact on the provision of end-of-life and/or after death and bereavement care
- Moral distress among decision makers and those that implement decisions regarding treatment prioritization or pediatric triage.

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## **HOW THE PAEDIATRIC PALLIATIVE CARE PANDEMIC PLANNING GUIDE WAS DEVELOPED**

The practice of pandemic planning in paediatric palliative care is a new and evolving practice.

Using a consensus-building process, a group of health care providers, researchers, pandemic planning experts and bereaved parents joined together to consult on and share their vision for pandemic practices that could be used in paediatric palliative care across Canada. This consultation included a review of current international pandemic practices and guidelines (see reference and links sections).

The resulting document, The Paediatric Palliative Care Pandemic Planning Guide, provides a framework for health care settings to use in order to provide a consistent approach to child and family care for children with life threatening illnesses during a pandemic.



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## HOW TO USE THIS GUIDE

The Paediatric Palliative Care Pandemic Planning Guide is designed to guide health care professionals in establishing standards of practice, service delivery, program and policy for caring for children with life threatening illnesses throughout the various phases of a pandemic. Its goal is to promote a consistent approach to pandemic care for this vulnerable population across Canada while acknowledging the need for flexibility within the healthcare delivery system. It is recognized that while the goal is to provide a consistent standard of practice, health care settings differ in their size, populations served, and in the way that they develop and function and therefore, this Guide is intended to help organizations develop procedures, policies and strategies that will help guide their pandemic practice.

### **Why a National Model for Paediatric Palliative Care Pandemic Planning?**

A standard approach to paediatric palliative care pandemic care will help to:

- ❖ Ensure that all children and families have access to high quality care.
- ❖ Support health care providers and organizations in the identification of child and family concerns and the implementation of recommended care and resources required to provide family- centred palliative care.
- ❖ Ensure that all health care providers and caregivers are knowledgeable and skilled in paediatric pandemic practices and have the resources that they need to fulfill their role.
- ❖ Identify any gaps in care and encourage formal caregivers to expand their services or develop partnerships with other health care organizations and caregivers to fill the gaps.

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## THE PAEDIATRIC PALLIATIVE CARE PANDEMIC PLANNING GUIDE

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### **Ethical Framework & Best Interests of the Child**

These guidelines are principle driven with a focus on quality of life, family-centered care, high quality palliative, end-of-life and bereavement care and value of life regardless of age, level of disability or complexity of a previous health condition, during a pandemic.

- Every human life regardless of age, gender, diagnosis, complexity of care or disability is considered equal.
- Regardless of allocation of resources, all children are entitled to maximized quality of life and minimized pain and suffering.
- Children with life threatening conditions receiving inpatient palliative or end-of-life care will be treated with an open and honest balance between optimal patient/family care and potential imposition/disruption due to pandemic-related processes.
- Information will be shared with families and children about pandemic practices in a timely, ongoing, truthful and consistent manner.
- Best interest of the child includes: respect for the child's role in decision making, respect for the parents'/guardians' role in decision making, benefit/imposition balance, truth telling, and privacy & confidentiality.

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## Planning Steps for a Pandemic Crisis

Pandemic preparedness requires significant resources before, during and after the occurrence of a pandemic outbreak.

### Pre-Pandemic Planning & Coordination

- ❖ Develop a multidisciplinary, interagency/multi-sectoral task group including members who have experience in palliative care.
- ❖ Build on and mobilize internal, local and regional capacities and resources of individuals, families and communities.
- ❖ Review and revise existing policies and procedures and revise accordingly.
- ❖ Develop staffing plans and decision making frameworks regarding workload priorities, reduction of non-essential services and re-deployment as required.
- ❖ Ensure that children with life limiting conditions have access to vaccines and anti-virals.
- ❖ Promote and educate families caring for children at home on hygiene practices to prevent or reduce potential risk for infection.
- ❖ Develop risk communication strategies to ensure that families have access to preventative, transparent and honest information regarding a pandemic outbreak.
- ❖ Develop psychosocial strategies to support health care workers and families relative to potential fear and anxiety.
- ❖ Create patient care opportunities with community partners and children's hospices for when hospital admissions are at capacity.
- ❖ Create a communication plan to ensure that updated and relevant information is being received and communicated to key partners.
- ❖ Create a method of assessing the needs of those providing essential services and develop a psychosocial plan for support.

## Pandemic Start & Peak

- ❖ Implement pandemic response.
- ❖ Provide continuous communication updates on the state of the pandemic, measures to manage risk and changes to routines and practices including infection control and isolation practices procedures.

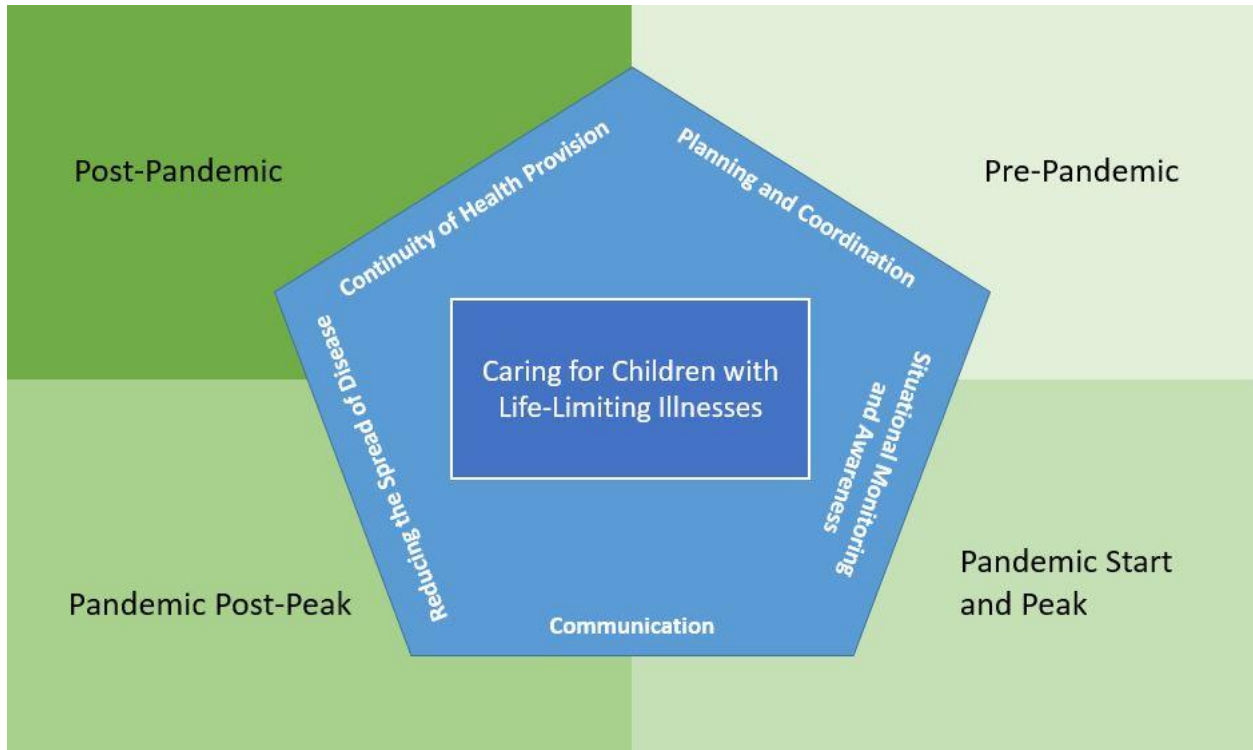
## Peak/Post-Peak

- ❖ During the outbreak, review, evaluate and modify, as needed: (i) practices, (ii) policies, (iii) local capacity, and (iv) the emotional well-being of health care providers.

## Post-Pandemic

- ❖ Publicly acknowledge contributions of all providers, organizations and communities and communicate lessons learned.
- ❖ Assess, review and evaluate based on lessons learned; consider the need for any transitional or long term services required.
- ❖ Integrate lessons learned into communication activities and planning for a potential subsequent outbreak.
- ❖ Assess the financial impact of the pandemic response.
- ❖ Implement work force resiliency and stress management programs for staff and organizations.
- ❖ Assess the child and family experience and need for long term support.

## Schematic of Pandemic Phases



*Adapted from the WHO's pandemic phase descriptions and main actions by phase  
[www.who.int/influenza/.../pandemic\\_phase\\_descriptions\\_and\\_actions.pdf](http://www.who.int/influenza/.../pandemic_phase_descriptions_and_actions.pdf)*

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## Paediatric Advanced Care Teams/Palliative and Bereavement Care Services

Specialized palliative care teams will implement prompt and effective team communication and coordination through regular team rounds, daily face to face, telephone or email communication in order to:

- ❖ Prioritize workload for the day.
- ❖ Review and share hospital and community pandemic guidelines and updates.
- ❖ Review and implement a staffing plan in the case of staff sickness, workload, staff secondment or redeployment.
- ❖ Apply optimal practices related to the application of end of life and bereavement care priorities and strategies in a health crisis context (as outlined below).
- ❖ Ensure and promote staff morale and well-being.
- ❖ Provide direction to complementary therapists, contract employees, research staff, volunteers and students/trainees.

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## Managing Patient Priorities & Employee Workload

- I. Children with significant pain and symptom management needs and/or who require end-of-life care and are receiving palliative care in the community will be provided care by palliative care teams directly or guidance will be provided by palliative care teams to an appropriate community caregiver and/or family member. If possible and safe, given pandemic conditions and staff availability, home visits will be provided by palliative care teams if difficult symptoms cannot be managed to reduce negative lasting effects of significant distress at end of life. All efforts will be made to maintain children in the community in order to reduce the overload on inpatient resources; however when a hospital death has been identified as preferred by a family, a hospital admission will be seriously reviewed for consideration.
- II. Children with life threatening conditions who are hospitalized when a pandemic occurs will continue to receive quality palliative and/or end-of-life care by a palliative care team, those with palliative care expertise or under the guidance of the palliative care team.
- III. Children who become rapidly ill due to a pandemic (expected to die quickly) will receive direct or indirect care or guidance by a palliative care team.

- IV. Children who are stable but receiving palliative care at home by a palliative care team will not receive home visits, but regular contact through telephone calls will continue as per the child’s plan of care, as possible.
- V. Routine clinic visits, home visits and/or school visits will be cancelled, depending on the determined level of risk and closure guidelines.
- VI. The need for non-essential clinical, support services, educational and research activities will be reviewed using a pre-pandemic decision making framework and resources may be deployed or reduced accordingly.

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## **Staffing Plan**

The palliative care service will work out a staffing plan that manages the possibilities of loss of staff due to illness and/or the influx of patients requiring palliative care services. This may include:

- ❖ Utilizing a “roster” of hospitalists and/or paediatricians with training in palliative care (i.e. residents, fellows, etc.) and/or hospital physicians with experience in palliative/end-of-life care.
- ❖ Utilizing a “roster” of nurses with similar training and/or experience as described above.
- ❖ Utilizing a “roster” of staff with expertise in psychosocial support, bereavement, death and dying, support to families (i.e. social workers, nurses, psychologists, child life specialists).
- ❖ Utilizing an identified roster of expert community care health care providers that could be called upon to take over or share in the care of children at home.

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## **Children’s Hospice**

It is anticipated that community hospices will develop their own policies for communication and care. Hospitals will seek to ensure sharing of updates with these organizations on a regular basis.

Recommendations include:

- I. Consideration of emergency respite for palliative children who are stable but require palliative/end-of-life care when a parent or caregiver becomes unwell.

- II. Consideration of admitting children to hospice from home with significant symptom management needs who are receiving palliative/end-of-life care in order to reduce overload on acute care hospitals and community caregivers.

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## Children's Community Health Care Teams

It is anticipated that home care services, and children's community health care teams will develop their own policies for communication and care. Hospitals will seek to ensure sharing of these updates on a regular basis.

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## Basic Symptom Management

- ❖ Discontinuation of inappropriate medical and nursing interventions such as blood tests, routine observations, turning, non-essential medications.
- ❖ Anticipatory prescribing to ensure that "as required" medications are available in advance.
- ❖ Utilization of non-pharmacological measures should be implemented and may include:
  - Comfort, reassurance, and explanation
  - Repositioning, suctioning for excess respiratory tract secretions
  - Gentle physiotherapy for breathlessness
  - Relaxation, massage, distraction, music/art, guided imagery for distress, pain, anxiety.

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## Communication

- ❖ Discussions with the child (when able/capable) and family should centre on the child's prognosis, plan of care, necessary infection control measures, any advance directives, and religious, cultural and/or spiritual needs.
- ❖ Communication should be truth based (including openness about death and dying), calm, and compassionate.
- ❖ Useful, consistent, understandable and accurate information will be provided to health care providers and families throughout all phases of the pandemic including regular updates.
- ❖ Ongoing and timely discussion about the impacts of the pandemic on care delivery and specifically on end-of- life care, will be a priority.



- ❖ Infection prevention and control procedures require creative communication strategies so that families may communicate with each other and with health care providers regarding key treatment decisions, anticipatory grief, end-of-life care and grief support.

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## **Families as Partners in Care & Hospital Visiting Policies**

- ❖ Visitation policies are guided by infection control practices but should be based on the importance of maintaining family relationships and social supports, and understanding the difference between visitation and vital access to family members who are key partners in a child's care. Family members include: parents, siblings, grandparents and others that the child identifies as a key social relationship.
- ❖ Family access policies should be flexible to ensure, if at all possible, that family members are enabled to be present for important events at end-of-life and/or after a child's death (e.g. baptism, last rites, saying goodbye to a dying child, gathering mementos). The potential risk to restricting family absence during these crucial moments can entail long term complicated grief for family members after the child has died.
- ❖ At times of restricted visitation other creative strategies should be implemented to ensure that children are not isolated, family bonds are continued and that parental burden is limited. These strategies may include: the use of videoconferencing or digital mediums such as the web (CarePages and instant communication networks) to maintain communication links between hospitalized children and their family members or designated hospital spaces that allow for family congregation.

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## **Infection Prevention and Control**

Infection prevention and control practices and policies should be upheld. However, in consultation with Infection prevention and Control services, consideration should be taken to adapt existing policies and practices to facilitate communication and connection between children, family members and health care providers.

- ❖ Masks required by health care providers to protect from potential infection, however policies should consider: the need for high level communication when discussing end-of-life decisions and other key death and dying discussions between family members and health care providers thereby finding alternative ways to communicate.
- ❖ Additional precautions (e.g. isolation procedures) and visitor restriction policies adapted to minimize child and family separation especially for important rituals (such as last rights, christenings or baptisms), during end-of-life or active dying or withdrawal of treatment. Adaptive and flexible policies may include: use of specialized patient and/or palliative care family rooms, videoconferencing, creative use of social media, flexible visiting policies that minimize restrictions to the number of family visitors, and access to viewing rooms, the morgue and bereavement practices that are preferred by the family.
- ❖ Flexible infection prevention and control policies and procedures that promote family participation in after death practices when possible (such as shrouding and cleansing a child's body)

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### **Information Sharing and Communication Strategies**

- ❖ Information sharing with families and children should be based on rapid, truthful honest and consistent information such that information, policies and practices are understood, and consistently applied. Variations are based on child/family need.
- ❖ Information will be shared in a variety of methods (e.g., posters, web, face to face, designated telephone lines and message centres).
- ❖ Information should address local cultural sensitivities, public beliefs and other considerations (such as rural and remote issues).

More specific communication strategies can be found at The Canadian Pandemic Influenza Plan for the Health Sector: <http://www.phac-aspc.gc.ca/cpip-pclcpi/ann-p-eng.php>.

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## Advance Care Planning

- ❖ Children (when able/capable) and their families should be given opportunities to discuss their wishes and needs and how they may best be met in order to ensure quality of life and best interests of the child. This includes: withholding or withdrawing life sustaining treatment, resuscitation, preferred location of death, tissue/organ donation, plans for the child's belongings etc.
- ❖ These principles should continue to apply to the best of everyone's ability even in the event of sudden or unexpected changes in a child's condition.

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## After Death Care of Child and Family

Principles and practices related to after death care of a child and his or her family require a commitment to care even in the event of a pandemic which may place a tremendous strain on organizational resources. Quality after death care is crucial in supporting healthy family grieving.

### At Time of Death

- ❖ Families should be asked if they have any particular wishes, rituals or customs regarding the care of the child after the death and efforts will be made to support those requests.
- ❖ Implement opportunities for legacy making and mementos.
- ❖ Implement hospital practices regarding after death care such as a Bereavement or After Death Check List.
- ❖ Sensitive discussion regarding tissue/organ donation may be revisited at this time.

### Preparation of the Child's Body

- ❖ Families will be provided with opportunities to remain with their child's body and to assist in cleaning, shrouding, touching or other preparation or cultural rituals they may request (exceptions may be required based on infection control practices, however efforts should be made to encourage family inclusion in this care aspect when possible).
- ❖ Hospital policies regarding the care of the child's body are based on dignity and compassion.

### **Transportation and Release of the Child's Body**

- ❖ The child's body is transported in a way that respects the dignity and privacy of the child and of other hospitalized children.

### **Death of Child Outside of Hospital**

- ❖ For a planned death at home, the palliative care team will provide direct care or provide guidance regarding declaration of death, post mortem examination and tissue/organ retrieval.
- ❖ Compassionate acknowledgement and access to bereavement care will be made available to the family.

### **Quiet Room & the Morgue**

- ❖ Families will be given as much time as possible to remain with their child after death on the inpatient unit, however some rituals and customs require additional presence with the child. Efforts will be made to support requests to view the child's body in the hospital's Quiet Room and to provide support to families during this time.

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## **Bereavement Care**

- ❖ Family members are offered bereavement care following the death of the child. This care includes: a compassionate acknowledgement of the child's death, emotional and practical support, an assessment of family coping, and help accessing other resources for grief counseling as requested by family members.
- ❖ Hospital policies and procedures (such as a Bereavement Check List) are implemented.

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## **Psychosocial Care for Health Care Providers**

- ❖ Psychosocial care for health care providers during a pandemic is crucial given the potential for extreme occupational stress, heightened fear/anxiety regarding personal safety, multiple care giving demands, moral distress and increased childhood deaths. Psychosocial interventions should be pre-planned and may

include, as example, staff education regarding cognitive, behavioural and emotional signs of distress, a support hotline, and access to psychological supports.

## LINKS

Public Health Agency of Canada website at: <http://www.phac-aspc.gc.ca/influenza/pandemic-eng.php>

Toronto Public Health. Communicable Disease Control. Pandemic Influenza FAQ website at: <http://www1.toronto.ca/wps/portal/contentonly?vgnextoid=222f5ce6dfb31410VgnVCM10000071d60f89RCRD&vgnextchannel=74422d6855e02410VgnVCM10000071d60f89RCRD>

Canadian Paediatric Society website at: <http://www.cps.ca/en/>

Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice website at: [http://www.chpca.net/resource\\_doc\\_library/PediatricNorms\\_of\\_Practice\\_March\\_31\\_2006\\_English.pdf](http://www.chpca.net/resource_doc_library/PediatricNorms_of_Practice_March_31_2006_English.pdf)

The Canadian Pandemic Influenza Plan for the Health Sector website at: <http://www.phac-aspc.gc.ca/cpip-pclcpi/pref-eng.php>

Public Health Agency of Canada: The Canadian Pandemic Influenza Plan for the Health Sector: Annex P Pandemic Influenza Psychosocial Annex website at: <http://www.phac-aspc.gc.ca/cpip-pclcpi/ann-p-eng.php>

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Centres for Disease Control and Prevention: Ethical Guidance for Public Health Emergency Preparedness and Response: Highlighting Ethics and Values in a Vital Public Health Service, <http://www.cdc.gov/od/science/integrity/phethics/ESdocuments.htm>

College of Nurses of Ontario: Pandemic Planning. <http://www.cno.org/learn-about-standards-guidelines/educational-tools/pandemic-planning/>

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