

The In-Hospital Presence of Family and Loved Ones during COVID-19 Restrictions: A Position Statement from the Provincial Pediatric Palliative Care Steering Committee (Version Date: January 18, 2021)

It is an accepted principle of pediatric palliative care that a child* receiving end-of-life care should have their preferred access to important family members and friends. The social, emotional, psychological, and spiritual benefits of the supportive presence of family and close friends are immediate for the child, while both immediate and long-lasting for the family.

The COVID-19 pandemic has created immense challenges for healthcare providers and the healthcare system. Although the need to control the spread of COVID-19 is well accepted, limiting children's access to family and significant others causes great distress for all involved.

The Provincial Pediatric Palliative Care Steering Committee (PPPC-SC) is calling upon all hospitals across Ontario that support children receiving end-of-life care (believed to be in the last days to weeks of life) to enable them to have access to their family and loved ones, including siblings and friends, and to be cared for in the setting they choose (including at home).

Provincial Expert Opinion Statement

We believe children receiving end-of-life care in an institutional setting should be supported by family and loved ones as defined by the child and guardians in consultation with the healthcare team.

We believe visits by those closest to the patient, **as defined by the child and guardians in consultation with the healthcare team**, who pass institutional COVID-19 screening protocols, should be enabled and encouraged. We believe children can be included in this select group, provided they have capacity to understand the expectations of them in respect of personal protective equipment.

In order to facilitate this practice, we believe that loved ones attending an institution to support a child receiving end-of-life care should be supported to uphold public health recommendations and the institution's infection control policies.

The overarching principle driving these concepts remains and must be the primacy of compassion and the presence of the family and members of the identified select group throughout the end-of-life care of the child, with appropriate application of the principles of pediatric palliative care, in a manner that supports the safety of all involved in that care.

Input for this position statement was solicited from all members of the PPPC-SC and its Family Advisory Council. These guiding principles are offered for consideration by institutions that provide pediatric palliative care. The PPPC-SC acknowledges the prerogative of each institution to develop its own detailed policies in accordance with the particularities of that institution. However, we believe that the importance of the presence of loved ones at the end of a child's life is incalculable and can be balanced with the need for safety and infection control to protect healthcare workers and the broader community.

* Throughout this document the terms 'child' and 'children' will be used to represent pediatric patients of any age, including infants, children, and adolescents.

Appendix A: Suggested Actions to Support the Implementation of the PPC-SC Opinion Statement

1. **We believe children receiving end-of-life care in an institutional setting should be supported by family and loved ones as defined by the child and guardians in consultation with the healthcare team.** Institutions may wish to:
 - a. Encourage families to choose a select group that is small enough to facilitate COVID-19 tracing if needed.
 - b. Limit access to the child to members of the group identified by the child and family.
 - c. Assess the capacity of children in the group to comply with infection control requirements.

2. **In order to facilitate this practice, we believe that loved ones attending an institution to support a child receiving end-of-life care should be aided in upholding public health recommendations and the institution's infection control policies.** Institutions may wish to:
 - a. Establish and clearly communicate infection control protocols, e.g., regarding correct use of masks and other personal protective equipment, handwashing, and any exceptions to these protocols.
 - b. Require members of the select group to observe formal screening and infection control protocols, and refrain from visiting if they have any symptoms of COVID-19.
 - c. Encourage members of the select group to undergo COVID-19 testing according to provincial public health screening criteria.
 - d. Encourage members of the select group to limit their own close social contacts to other members of the select group as much as possible.
 - e. Encourage outdoor visits wherever possible.
 - f. Encourage and support virtual or telephone visits with friends and extended family.

3. **In addition,** institutions may wish to:
 - a. Develop a flexible and compassionate “pediatric end-of-life care plan during COVID-19” in partnership with their family advisory bodies. This plan may include care pathways and clear policies and guidelines for staff and visitors, in understandable language, that define expectations and required behaviours and practices.
 - b. Identify and provide teaching tools in a variety of formats (e.g., video, written, plain language, other languages, graphics) to inform families of the expectations of the institution.
 - c. Make sure all staff are aware of what they can do to support families to observe safe practices.
 - d. Provide primary nursing care and identify a core group of caregivers to support the child and family.
 - e. Ensure adequate supply of personal protective equipment for staff, family, and visitors.
 - f. Provide care to the child in a room with clear and direct access for their select group of visitors (e.g., close to an entrance/exit).
 - g. Ensure that the family has adequate space to gather. Instruct the family to contain their visits to that space. Where possible, institutions will allocate larger rooms to larger families.
 - h. Develop protocols and identify staff to take responsibility for enforcing compliance with the expectations for visitors. Ensure that the family's clinical team does not have this responsibility in order to preserve their bond/relationship with the family and child.

While the focus of this statement is children receiving end-of-life care, we believe that the principles outlined herein may be applicable for any children and families facing critical illness. In such circumstances, we encourage pediatric institutions to take a case-based approach.

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