

## Paediatric palliative care

Paediatric palliative care is an emerging interest among physicians. In order to develop paediatric palliative care services in a logical and evidence-based manner, it is important to better define who needs this type of care. This survey aims to establish which children, in Canada, are perceived by their paediatricians to need specialist palliative care input, and what they feel that input should ideally provide. Survey results could inform on best practices for development in paediatric palliative care services.

**Your contribution is greatly appreciated.**

**1. What is your definition of palliative care?** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**2. For what types of conditions do you think palliative care is needed? (Check all that apply)**

Conditions for which curative treatment is possible but may fail (e.g., advanced or progressive cancer, complex and severe congenital heart disease)

Conditions requiring intensive long-term treatment aimed at maintaining quality of life (e.g., severe epidermolysis bullosa, severe immunodeficiencies, renal failure in which dialysis and/or transplantation are not indicated, muscular dystrophy)

Progressive conditions in which treatment is exclusively palliative after diagnosis (e.g., progressive metabolic disorders, certain chromosomal abnormalities such as trisomy 13 or 18)

Conditions involving severe, non-progressive disability, causing extreme vulnerability to health complications (e.g., severe cerebral palsy with recurrent infections or difficult to control symptoms, extreme prematurity, severe brain malformation)

Other(s), specify: \_\_\_\_\_

**3. Over the past month, how many children/youth have you seen who had any kind of palliative care need?** \_\_\_\_\_  
 Of these patients: how many did you care for directly? \_\_\_\_\_ how many did you refer to another consultant? \_\_\_\_\_  
 how many did you refer to a chronic care facility? \_\_\_\_\_

**4. What are the palliative care needs of your patients? (Check all that apply)**

Coordination of services in the community

Physical symptom management

Support for family (psychological, emotional, spiritual)

Support for child (psychological, emotional, spiritual)

Practical/financial support

Respite care: home \_\_\_\_\_ chronic care facility \_\_\_\_\_ other, specify: \_\_\_\_\_

Care at the time of death

Bereavement care

Discussion of prognosis with child

Discussion of prognosis with family

Other, specify: \_\_\_\_\_

**5. Do you feel your patients are receiving all the services you have identified?** Yes \_\_\_\_\_ No \_\_\_\_\_  
 If no, explain: \_\_\_\_\_  
 \_\_\_\_\_

**6. Do you have access to the following? (Check all that apply)**

Hospital or university-based palliative care: team \_\_\_\_\_ → paediatric \_\_\_\_\_ adult \_\_\_\_\_ both \_\_\_\_\_  
 services \_\_\_\_\_ → paediatric \_\_\_\_\_ adult \_\_\_\_\_ both \_\_\_\_\_

Community palliative care: team \_\_\_\_\_ → paediatric \_\_\_\_\_ adult \_\_\_\_\_ both \_\_\_\_\_  
 services \_\_\_\_\_ → paediatric \_\_\_\_\_ adult \_\_\_\_\_ both \_\_\_\_\_

Other, specify: \_\_\_\_\_

**7. As a practicing physician, specify the supports you require to manage your patients with palliative care needs:**  
 \_\_\_\_\_  
 \_\_\_\_\_

**Please return this survey with your monthly reporting form. Thank you for your participation.**