



## Invitation for Engagement for Provincial Pediatric Advance Care Planning Project

### Opportunity:

Canuck Place Children's Hospice (CPCH) extends an invitation to siblings of individuals with a serious illness<sup>1</sup> in British Columbia to share their valuable perspectives on Pediatric Advance Care Planning<sup>2</sup> (pACP). We recognize that siblings play a crucial role in the lives of individuals facing serious illnesses, and your insights are invaluable.

In addition, we hope to have representation from siblings who may also identify with one or more of the following:

- You may have a diverse cultural or social background in British Columbia.
- You may have a sibling with neurological developmental diversity and a serious illness.
- Your sibling may be living with a condition that brings an uncertain future.
- You may have experience with your sibling receiving pediatric palliative care.

To participate, you need access to a computer and familiarity with Zoom. Additionally, your commitment to a two-hour virtual session is required.

This opportunity will provide a platform for you to share your experiences related to pACP. The sessions will be facilitated by a Young Adult Engagement Advisor with lived experience and a counselor from CPCH with a focus on supporting the voices of siblings of children with serious illnesses.

Goals of the opportunity are:

- To explore, listen, and understand the experiences, issues, and needs of siblings surrounding pACP.
- To develop an understanding of how best to have these conversations
- To integrate your unique perspective and expertise as a sibling of an individual living with a serious illness.

For participation, you need access to a computer and knowledge of the Zoom platform, as well as be able to commit to a two-hour virtual session.

### Date for the virtual session is:

- Wednesday October 25<sup>th</sup> 4pm-6:00pm PST

Your perspective will inform the provincial process of pACP and enhance care for children/youth/young adults living with a serious illness as we continue to work on this initiative. Compensation for time and reimbursement for any necessary expenses is supported for this engagement session and aligns with engagement standards (\$25/hour). The facilitator(s) will be speaking in English, if you require interpretation, services are available, please let us know.

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<sup>1</sup> *Serious illness*: condition that impacts life and daily functioning with unknowns about the future and/or condition that can be difficult to manage in symptoms, treatments or family stress.

<sup>2</sup> *Pediatric advance care planning* (pACP) are ongoing conversations between children, their families and their healthcare providers to explore and understand the values, beliefs and wishes of the child and family. This conversation supports shared decision-making when a child's health condition is fragile and/or future planning for the care of the child if their health condition were to worsen.

*This engagement opportunity aligns with the values and principles of the Canuck Place Family Engagement Framework, co-designed by the Family Coalition.*



## **Background**

CPCH along with Child Health BC, Children's and Women's Indigenous Health, Perinatal Services BC and BC Children's Hospital are working together for a provincial approach to pACP. This is a two-year Ministry of Health priority project. The goal of the project is to improve the delivery of pACP services for children/youth/young adults with a serious illness and their families throughout British Columbia.

## **What we aim to support when participating:**

We recognize that siblings across BC come with a variety of experiences, and all voices are valued. Canuck Place will provide a safe, confidential, and supportive online space for siblings to share their experiences with pACP by:

- Allowing the expression of feelings without fear of judgment.
- Providing peer support through the facilitation of a youth/young adult engagement advisor and CPCH counselor.
- Offering an opportunity to connect with siblings across BC who are familiar with the process of pediatric advance care planning services.
- Maintaining a safe space that does not identify individuals, allowing siblings to share as much as they choose about their experiences.
- Offering an opportunity to debrief and access follow-up support if needed following the session.

We aim to engage siblings who represent different experiences, care populations, and demographics. If you are interested in participating in this opportunity or wish to learn more about this engagement session, please contact [familyexperience@canuckplace.org](mailto:familyexperience@canuckplace.org) by Wednesday, October 20th, 2023. Your voice and perspective matter greatly.

If you are a family member interested in this opportunity and sharing your perspective of supporting your child/youth/young adult with a serious illness or you are an adolescent/youth or young adult living with a serious illness, please see our family partner engagement opportunity or our adolescent/youth/young adult engagement opportunity <https://www.canuckplace.org/resource-hub/family-engagement-opportunities/>.

## **Family Engagement at CPCH**

Children and family are at the centre of the care provided at CPCH. We respond to the voices of our patients and families, and collaborate on improving care by working directly with families. This past year, CPCH, through the Family Engagement Coalition, invested in developing a comprehensive Family Engagement Framework to provide guiding principles, goals, opportunities, and processes to support our commitment to collaborative work with families. Partnering with families and acknowledging their living and lived experiences are vital and valuable components to improving our program services. The vision for the framework is to ensure consistent, safe, and respectful engagement with children, youth, and families at CPCH, to fully represent the diverse perspectives and promote continual improvement of pediatric palliative care and services.

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