



Written Submission for the Pre-Budget
Consultations in Advance of Budget 2021

Canuck Place Children's Hospice

August 2020

Recommendation

As the Federal Government examines funding opportunities in Budget 2021, it is imperative that funding for pediatric palliative care be included. In the \$19 Billion Safe Restart Agreement, support for vulnerable Canadians in palliative care was dedicated, but this does not include pediatric palliative care. Canuck Place Children's Hospice in British Columbia is one a number of organizations across the country providing this essential care during COVID-19 and beyond.

About Canuck Place Children's Hospice

Providing Specialized Services to BC's Sickest Children and their Caregivers

Canuck Place Children's Hospice (Canuck Place) is British Columbia's pediatric palliative care provider for children with life-threatening illnesses and the families who love them. Our team of physicians, nurses, counsellors, therapists, staff, and volunteers provide medical respite care, pain and symptom management, art, music, and recreation therapy, end-of-life care, grief, loss, and bereavement counselling, all at no cost to families.

Canuck Place operates 24-hours a day, 365 days a year, providing medical care for children with life-threatening illnesses from birth until age 19. More than 818 newborns, children and youth from across BC with life-threatening illnesses and their families receive care through Canuck Place each year. This care is provided through two hospices, one in Vancouver and one in Abbotsford. In addition we provide medical, and nursing care and psychosocial support in homes, hospitals and communities across the province. We provide the pediatric palliative care services for BC Children's and BC Women's hospitals.

Canuck Place receives both Provincial government funding, comprising about 40% of our annual operating budget, and private donations, the remaining 60%. All other pediatric hospices in Canada are primarily funded through their Provincial Health Ministries.

Demand for our services continues to grow. There has been a 26% increase of children and families in our care since 2016; however our support from the Provincial government has not changed.

Opened in 1995, Canuck Place was the first free-standing children's hospice in North America. Our top priority is always to provide the best possible care to the children and families we serve. To further that goal, we are also committed to the ongoing study, learning and research in pediatric palliative care. We are leaders in the field; host monthly rotations for senior Pediatrics residents, Pediatric Oncology Fellows, and Adult Palliative Medicine trainees fulfilling RCPSC and CCFP requirements, and our Medical Director is a CIHR funded researcher in the field. In addition, we have been recognized with Exemplary Standing by Accreditation Canada.

Our Services

Province-wide Support

Canuck Place's Enhanced Community Care Program improves rural health services by bringing responsive specialized care to families around BC where and when they need it. The Canuck Place clinical team provides assessment, care planning, pain and symptom management, follow-up support, and end-of-life care. With in-hospice, in-hospital and in-home care, telephone and video conferencing, and our 24-hour nursing line, families have access to care no matter where they reside in the province.

Respite for Caregivers

Caregiving without adequate supports can impact the whole family. Respite and family support are essential components to our program. We offer 24-hour in-house clinical care for children with or without their families. Admissions for pain and symptom changes or progression in diagnosis are “when required” and, in addition, each family can book up to 20 days of respite each year. Respite allows children the opportunity to receive clinical care and offers families much-needed rest, renewal and support.

Training for Health Care Providers

Canuck Place takes a leadership role in the development of pediatric palliative care standards in BC and nationally. Clinical leaders deliver education and training to health care professionals at B.C. Children’s Hospital and B.C. Women’s Hospital & Health Care Centre and in other communities within the province. We also provide clinical rotations in pediatric palliative care. In 2018-19, Canuck Place developed a guide and training sessions for clinicians on how to have Serious Illness Conversations with Children and Families. Last year, more than 150 physicians, nurses and social workers were trained at B.C. Children’s Hospital and Women’s Health Care Centre and training sessions occurred in Prince George, BC and Ottawa, ON. In addition, our nurse practitioner and one of our physicians have provided education in pediatric palliative care in India.

Recommendation

World Health Organization (WHO) Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

Pediatric palliative care is different than adult hospice care.

Pediatric palliative care is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. This care includes the management of distressing symptoms, provision of short respite breaks, end-of-life care and bereavement support.

Integral to effective pediatric palliative care is the support for the caregivers and service providers as they work through their own emotions and grief related to the care they are providing. The parents and caregivers are also providing care to the children, so the burden is considerable, given the expected death of their child before age 19.

Unlike adult patients, 70% of pediatric patients are living one year after initiating palliative care.

Addressing critical care gaps

In BC's adult health care system, each Health Authority has a designated palliative care team. The health authorities do not provide in home care to critically ill children. Canuck Place Children's Hospice is providing this service for children and families across the province.

Canuck Place is experiencing increased demand from children and families who need access to our programs, with a 76% increase in provincial community care since 2013. This increased demand impacts all areas of operations from infrastructure to technology.

Additionally, Canuck Place continued to provide critically-needed palliative care throughout the COVID-19 pandemic. As Canuck Place's patients, 77% of whom live outside Metro Vancouver, became more

isolated in their communities, we witnessed a dramatic increase in the number of requests for specialized home-based support through our Enhanced Community Care Program.

There are critical gaps in pediatric palliative care in BC that need to be addressed:

1. Ongoing operational needs: increase in demand for services

As a health charity providing critical care, we believe the Federal Government should consider the growing need for our services and the specialized resources needed to deliver care to some of Canada's most fragile children.

Canuck Place has seen a 48% increase in demand for our provincial consultation services since 2017. Patient care costs, including those associated to COVID-19 and PPE needs, have significantly exceeded our provincial government funding.

2. Technology upgrades

Our technology needs are unique. With our in-patient, in-community, and in-home care, telephone and video conferencing, and 24-hour nursing line, our families receive care no matter where they reside in the province, right where they need it.

The need for innovative technologies to support these unique patient needs has been exacerbated by COVID-19. We have seen a dramatic increase in families requiring specialized, home-based care delivered through new means, particularly telehealth.

We foresee virtual care becoming a central component of our care provision over the coming months and years. Canuck Place is a willing partner to the Government of Canada as it charts the strategic role in ensuring that health care is accessible to those in rural and remote communities when and where they need it most.

Supporting palliative care for children and youth

Due to the cancellation of upcoming fundraising events, Canuck Place has already experienced a significant loss of operational revenue. This, coupled with the increase in demand for our specialized services, means we require enhanced supports to effectively deliver critical care to vulnerable British Columbian families. We are funded less than 50% from provincial funding, and the remainder from donor funding. This gap has put increasing pressure on our need for donations from the public to support this critical care.

Canuck Place has had a longstanding role in strengthening high quality, compassionate, accessible and cost-effective palliative and end-of-life care. Canuck Place stands ready and committed to ensure that children and youth can always access the care that they need.

We appreciate that these past few months have created new challenges for organizations across Canada and we are grateful for the leadership of all Members of Parliament in supporting growing needs in our communities.

We hope to work with you to ensure all children and families are supported, and nobody gets left behind.

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