

Working Together for Pediatric Palliative Care in B.C.

As you may be aware, Canuck Place Children's Hospice offers pediatric palliative care for B.C. children and their families. I would like to invite you to learn more about our program and offer our support in caring for children and families in your community. Such support can happen through consultations, education or referrals to Canuck Place. We can connect through teleconferencing and videoconferencing for those outside the Lower Mainland.

Our Philosophy

The goal of our care is to enhance quality of life *for both child and family* when the child has a progressive life-threatening condition. We offer comprehensive, family-centered care throughout the progression of the child's illness and until the family no longer needs our services.

Conditions Accepted

We serve children ages 0-19. We also serve families in the prenatal stage whose fetus has been found to have a serious condition. The important factor for our program is the presence of a progressive, life-threatening condition. Progression meaning, on-going deterioration of health and/or functions. Life-threatening means the "child" is likely to not live into full adulthood (defined as early 20's). They may die either because of a progressive disease process or because of disease effects and complications. Some children/youth are within slowly progressing phases of their conditions, while others are acutely terminal.

For some of the conditions we see prognosis is easier to predict, i.e. the child with cancer who is getting worse despite maximal oncological therapy. For others, e.g., metabolic diseases, prognosis is harder to predict and the literature is often misleading.

We do not need absolute evidence that this specific child will not live until adulthood. Instead we look at several factors:

- The diagnosis. What is known about the diagnosis and the condition according to the best evidence in the literature, expert opinion and current epidemiology.
- This child's individual course. Within any given diagnosis, some children will progress faster than others.
- The presence of complications. Complications may either be due to the disease itself, or to the treatment.
- The readiness of the family to consider a palliative approach to care along the trajectory and enter a palliative care program

The diagnosis itself is not the full answer. There are children with multi-handicaps who are "progressing" by the nature of their condition and treatment. The child with a g-tube, j-tube, severe reflux, feeding intolerance, worsening seizures and unrelenting episodes of aspiration pneumonia is demonstrating "progressive decline", even though the diagnosis is static. Each case requires individual attention and review.

Family Matters

The willingness of the family to consider a palliative approach to care is important. In contrast to the older, often adult-oriented uses of the term 'palliative', in pediatrics we define it as the aspects of health-care addressing physical, emotional, social and spiritual comfort and quality of life. In our practice, we provide not just respite, recreation, school, etc., but a team approach to confronting the challenging issues around a child's likely early death. We do not require a "DNR" order; but we do require the readiness to engage in thinking about the life-limiting nature of the child's condition.

The Referral Process

If you believe a child is appropriate for our program, here are the steps to follow:

1. Call the Intake Nurse at Canuck Place Children's Hospice, 604-742-3476 or toll-free in B.C. at 1-877-882-2288 ext. 3476. If the referral is urgent, please call the nursing station at 604-742-3475
2. The Intake Nurse will follow-up on information from the child's physician, care provider and parents.
3. This information is reviewed by the Intake Team at Canuck Place.
4. If the child is eligible for the program, the parents/guardians are informed and advised of the programs available.

All of Canuck Place's services are available at no cost to families.

When a child and family are admitted to our program, they can access:

Family Support/ Medical Respite Care – 24 hour care of a child at the hospice, for short breaks, to give families time for rest and renewal. During this respite time Canuck Place nurses and physicians assess the child for disease progression and evaluate each child's medication and care plan. Counselling team members provide services to the child, siblings, parents and other family members. It is also during respite visits that the care team at Canuck Place has annual family team meetings with each child's family and/or caregivers to review how the child and family are doing on both a physical and psychosocial level. Depending on the number of children in the program, most families are offered up to 20 days of respite per year.

Symptom management – active care aimed at managing the adverse physical and emotional symptoms of a child's illness and/or side effects of treatments. Families can also call to discuss symptom management with a nurse, 24 hours a day, 7 days a week, who can then liaise with the physician on-call. It may then be determined that a symptom management admission is necessary. The length of stay is determined by the needs of the child and family and a discussion about the best location of care.

End-of-Life Care – comprehensive services for a child and family when the child's death is expected to be imminent. End-of-life care may occur in the hospice setting or through outreach support and services, if the family prefers the child die at home.

Counseling support and Bereavement Care - From the time of diagnosis, throughout their illness and after their death, Counseling support and Bereavement Care are offered for the child and their family members. Consultation and support are also made available to others involved in the child and family's life.

Care planning and consultations – Children and families do not have to come into the hospice to receive care once they are accepted to the program. Our team provides consultations with children and families and their care teams at any point along the journey. This may be a face to face meeting at a health care setting (e.g BCCH) or through telehealth videoconferencing or telephone. It is through these connections that care planning and coordination can be implemented which has been found to have many benefits.

A 24 hour 1-800 number is available to families, nurses, doctors and other care professionals from across B.C. to consult with Canuck Place doctors and nurses throughout all stages of the child's illness.

Canuck Place's interdisciplinary team includes:

Physicians	Grief counselors	Volunteers
Nurses	Social workers	Support staff
Recreation therapists	Chaplain	
Art, play and music therapists	Schoolteachers	

If you would like more information about our program, services, referrals, or consultations please contact the Intake Coordinator at 604-731-4847 or the Clinical Nurse Specialist at 604-742-3478 or toll-free in B.C. 1-877-882-2288 or e-mail intake@canuckplace.org