

# An Educational Program in a Pediatric Hospice Setting

Isabel Wood, BEd, Post Bac Dip, Dip Spec Ed

Canuck Place Children's Hospice, a family-centered pediatric hospice in Vancouver, Canada, provides family support and respite, pain and symptom management, and end-of-life care. One of the goals of pediatric hospice palliative care is to create an environment that supports a normal way of life and enhances quality of life. At Canuck Place, a unique school program for children with progressive life-threatening illnesses has been

set up to meet this goal. This article describes the Canuck Place educational program, gives insights into the importance and challenges of providing a complete school experience, and discusses the expanded role of the teacher in the pediatric hospice setting.

**Keywords:** palliative; pediatric; education; hospice; programming; classroom

## Introduction

One of the goals of pediatric hospice palliative care is to create an environment where children with progressive life-threatening illnesses and their families can, to the greatest extent possible, maintain a sense of normalcy and experience an enhanced quality of life. The routine of regular school attendance helps fulfill this goal while contributing positively to the social, emotional, physical, psychological, and spiritual needs of children with illness and their families.<sup>1,2</sup> Although the importance of education is becoming more recognized in the literature<sup>3,4</sup> and the charters of many pediatric hospices<sup>5,6</sup>, few institutions have actually implemented consistent educational programs.<sup>7</sup> Canuck Place Children's Hospice, a family-centred pediatric hospice in Vancouver, Canada, offers a unique school program that operates in partnership with the child's regular, or "home" school (the school that the child normally attends in his or her community when living at home). This article describes the Canuck Place educational program, gives insights into the importance

and challenges of providing a complete school experience, and discusses the expanded role of the teacher in the pediatric hospice setting.

## Description and Challenges of the School Program

### Overview

The school program at Canuck Place Children's Hospice supports more than 125 children from kindergarten to grade 12 from across British Columbia, Canada. Children aged 5 to 19 years admitted for family care and respite usually attend the school program for up to 1 week, on an average of 4 times from September to June. Children receiving pain and symptom management care may stay longer. Siblings of the children receiving end-of-life care may also attend school at the hospice for 1 or 2 days or as long as 6 weeks.

### Programming

The school day is divided into morning and afternoon sessions. The morning session, which runs from 9:00 AM to 12:00 noon, is the academic component of the program; students typically complete work brought with them from their home school during this time. The afternoon session, which runs from

From the Canuck Place Children's Hospice, Vancouver, British Columbia, Canada.

Address correspondence to: Isabel Wood, c/o Tanice Miller, Canuck Place Children's Hospice, 1690 Matthews Avenue, Vancouver, BC V6J 2T2, Canada; phone: (604) 731-4847; e-mail: [tmiller@canuckplace.org](mailto:tmiller@canuckplace.org).

**Table 1.** Programs and Interventions Used at Canuck Place to Meet the Needs of the Varied Student Population

Education Programs	Definitions	Examples of Interventions
Regular	Students fulfill the widely held learning expectations for their grade level	Work from home school or similar work is completed
Adapted	Students follow the regular curriculum for their grade level and will meet the learning outcomes as long as adaptations are made	Computer with scanning, reading, and writing software; writing support (scribe); more time for assignments or tests
Modified	Students follow a parallel program with learning objectives that enable the student to develop academic, social, and emotional skills but that do not meet the learning outcomes for their grade level	Shortened school day; parallel activities in subject areas; specially designed software programs; writing support (scribing); reading support

**Table 2.** Interventions Used at Canuck Place to Meet the Needs of the Nonverbal Population

General activities
Wide variety of multisensory equipment (simple, readily available equipment to more sophisticated, commercially bought equipment)
Stories
Music activities
Light board activities
Hand over hand artwork
Use of single switches to access games with a dice spinner
Activities designed to develop an understanding of cause and effect
Concrete choice making (reaching/eye pointing)
Choice making using pictures or symbols
Use of visual schedules or communication boards (hand made or commercial)
Cause and effect activities
Use of a single head or hand switch with toys, music, or computer software (see Figure 1)
Interventions for students with a well-developed understanding of cause and effect
Use of a wide variety of communication devices (simple to high-tech)
Use of single switches to access computer software
Use of students' individualized specialized equipment

1:00 to 3:00 PM, provides a chance for students to participate in outings, music therapy, arts and crafts, games, sports and playground activities under the direction of a recreational therapist. Presentations are also brought into the hospice from the community during this time.

Specific programming is provided to meet the needs of the varied student population at Canuck Place. In the 2006-2007 school year, more than half (56%) of the students were on modified programs whereas almost equal proportions of students were on adapted (24%) and regular (20%) programs (Table 1).

The makeup of the classroom changes frequently. For example, on any given day in the school room there may be verbal and nonverbal children present with different academic or communicative requirements that demand targeted interventions (Table 2).

Figure 1 depicts one such intervention currently in use at Canuck Place, a single switch and computer software that allows students to work on cause and effect activities.

Working around the ever-changing medical needs of students, including appointments, fluctuating energy levels, and frequent last-minute alterations in admissions that result in students arriving unannounced without books and assignments, is challenging. These unpredictable circumstances require flexibility and creativity on the part of the Vancouver School Board teacher, special education assistant, and trained volunteers that implement the program.

### Importance of the Program

Apart from promoting the development of mutual respect, cooperation, social responsibility, and individual worth, the Canuck Place school program adheres to the following principles:

*Respects children's rights.* Every child has a legal right to education in a system that respects diversity and has the capacity to address characteristics, interests, abilities, and learning needs.<sup>8</sup> The Association for Children's Palliative Care states that every child shall have access to education.<sup>5</sup> The National Council for Hospice and Specialist Palliative Care Services states that "provision of education to sick children is essential and a legal entitlement."<sup>6</sup>



Figure 1. Student using a single switch and computer software to work on cause and effect activities.

*Provides a sense of normalcy in the lives of children and their parents.* School is a regular part of children's lives and provides a connection to life right to the end.<sup>8,9</sup> In addition to providing routines and purpose, school can provide distractions from the worries of an illness.<sup>7</sup> School attendance helps the children see themselves as normal and helps their peers view them as normal. At school, the children are not seen as children with an illness but as students engaged in learning, exploring, discovering, creating, and developing abilities.<sup>7</sup>

*Provides opportunities for success and thus the development of positive self-esteem.* Learning activities can be designed so that children may be successful and feel that they have accomplished an important job for the day.<sup>10</sup> By following the children's Individual Education Plans (a written plan developed by an educational team which includes parents and appropriate professionals who are working with the child; plan consists of long- and short-term goals and includes modifications or adaptations and support which will be provided for the child) developed by an educational team at their home school, the students can continue working toward their goals while at the hospice. Children working on regular or adapted programs can also continue to work on their assignments so that they are not behind when they return to their home school.<sup>7</sup>

*Provides opportunities to develop friendships.* Friends allow children to share thoughts on an equal basis. School provides an opportunity for children to connect with their peers. Peer friendships enrich children's lives and provide support in ways that only children can.<sup>11</sup> Children of similar ages and illnesses are frequently booked into the hospice at the same time, and as their families get to know each other through social events and support groups, friendships are formed. Contact with classmates at the children's home schools, either by email or by visits, is also encouraged to maintain a sense of belonging.<sup>7</sup>

### Role of the Teacher

The flexible learning program offered at Canuck Place is intended to support the existing program at the child's home school. For this reason, communication between the Canuck Place teacher and the home school teacher<sup>3</sup> (the child's teacher at the school which the child normally attends in his or her community when living at home) is crucial before and during each child's hospice visit. The Canuck Place teacher obtains and reviews copies of students' Individual Education Plans from their home schools to ensure that they continue working toward their educational goals while at the hospice. In turn, the child's home school teachers are able to use these conversations with the Canuck Place teacher as a way of broadening their understanding and discovering means of enhancing the quality of life of a child with a progressive life-threatening illness.<sup>9</sup> The home school teacher collects information about the child's illness, such as the effect it may have on school performance, limitations or special accommodations that are needed, social or emotional issues, and information about siblings.

Besides informing the child's home school teacher, the Canuck Place teacher also provides information to the Canuck Place team to enhance the holistic care for children and their families while they are at the hospice. Communication with parents takes place mainly at the hospice and through phone calls. At the request of a parent, the hospice teacher will act as an advocate for the student at his or her home school. This may take the form of recommending equipment or resources that have been successfully used at Canuck Place, acting as a fresh set of eyes, or acting as a mediator between parents and the home school if difficulties arise. The Canuck Place teacher is often able to assist the parent by suggesting the appropriate personnel in the educational system to approach.

## Conclusions

Canuck Place Children's Hospice, with the support of the provincial government and Vancouver School Board, provides a school program that supports the existing program at home schools. Children attending the hospice school program gain the benefit of participating in the normal routines of childhood, belonging to a supportive network of staff and students, and being challenged by other members of their peer group in a safe environment where they are not defined by their illness. Students are permitted an escape from their illness with the provision of academic and social activities, which give them opportunities to be successful and to develop their abilities despite any existing limitations. The Canuck Place teacher has an integral role as an advocate and educator, providing valuable information about the physical, cognitive, psychosocial, and emotional toll that illness can have upon a child to their home school teachers. Canuck Place has been a model for pediatric hospice care since opening its doors in 1995. By recognizing the importance that education and learning play in the lives of children and by ensuring that its school program continues to grow and flourish, Canuck Place provides an example to other new and established hospices of the role that a school program can play in enhancing the quality of life for children with progressive life-threatening illnesses and their families.

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