



Pediatric Oncology Palliative Care in BC

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I couldn't believe what they were telling me. The oncologist said she couldn't cure her cancer. I didn't believe her. How could this be? We had been fighting cancer for over half of her 12 years. Through chemo, radiation, bone marrow transplant, ICU stays, times when they told us she wouldn't make it, recovery from infections that almost killed her. Was this all for nothing? I was so angry with that doctor. No way were we going to give up. She was a fighter and we would continue to fight. The doctor said we should try to make her quality of life as good as it could be for as long as it could be. That wasn't good enough for us. ~mother of a child with progressive cancer~

Although the cure rate in pediatric oncology has increased over the years, in spite of our best efforts some children will die. In BC, each year, approximately 120 children are diagnosed with cancer and approximately 27 children die of cancer or cancer-related treatment.

Our challenges are many: providing clinical, practical, emotional, spiritual and psychosocial care as we help families make the transition from acute to palliative care. Our ultimate goals are always to enable hope, to extend life with good quality for as long as possible and to lessen suffering. The above quote describes how many parents react when given the news that their child will die. Some will fight against this devastating news. Some won't believe us; anger, despair, overwhelming grief, shock, numbness, are only some of the

emotions that overcome families. Parents are ultimately responsible for decisions relating to their children's care and it is important that we are compassionate, knowledgeable and non-judgmental as we walk this journey with them.

Currently, we have several families facing the transition from acute to palliative care. As we work with those children who are diagnosed with a poor prognosis, who have relapsed and whose cancer has progressed in spite of the best that science has to offer, our goals and hopes change. Wolfe and her colleagues (2000) found that parents can live with dual goals: hope for a cure, a miracle; and the goal of good quality of life for as long as possible. Toward that goal, palliative chemotherapy, radiation therapy or surgery may be useful in lessening suffering and managing symptoms. These goals are carefully explained to parents, and reviewed periodically. Some children and parents decide to participate in Phase I or II studies, where the goal is to determine toxicity or efficacy of new anti-cancer agents, not cure.

The Canadian Hospice Palliative Care

Association is in the process of consensus-building to make newly developed Norms of Practice for Pediatric Palliative Care a national document (www.cnppc.ca). A small interdisciplinary working group in pediatric oncology at BC Children's Hospital (BCCH) has further adapted these to describe how we practice pediatric oncology palliative care and to describe

the foundation upon which to build our practice. We plan to share this document with our community partners as a starting point for working together to provide the best evidence-based pediatric oncology palliative care possible.

The Children's Oncology Group and the Association of Pediatric Oncology Nurses are working on a joint project whose goal is to provide evidence-based clinical guidelines in pediatric oncology palliative care, including symptom management, transitioning into palliative care, and issues for professional caregivers. Two members of our BCCH team are helping to write these guidelines.

Most children who are receiving palliative care prefer to be at home. Helping children and families be wherever they want/need to be is another goal. Communication and collaboration with community-based caregivers are essential to providing the best care possible. The BCCH oncology team will maintain some involvement with the family throughout the palliative care phase, whether as

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Emily Inglis 1990-2002

A precocious young lady whose personality always made her presence known during her three year battle with neuroblastoma. Her prolific artwork often decorated the Oncology Department and reflected her love of family, friends, soccer and animals.



Around the province...

Kelowna Pediatric Oncology Program

The Pediatric Oncology Program at Kelowna General Hospital provides ongoing chemotherapy and supportive care to children from Kelowna in partnership with BC Children's Hospital. This allows families to remain closer to home for longer periods, helping to alleviate some of the stress and anxiety faced by our families. Information is constantly being shared between the Kelowna team of care providers and the primary nurses and oncologists at BC Children's Hospital, providing seamless care to our children and families.

Our team consists of six pediatricians and a core group of nurses who care for children and their families during their treatment protocols. Social work and nutrition support is also available. We are also fortunate to have the support of our Anesthetist Department, as they are always available and willing to provide sedation support when needed and at the convenience of our treatment team and families. The level of care provided falls between levels 2 & 3. The location of chemotherapy treatment is negotiated between the care providers here and at BC

Children's Hospital, and in consultation with the families as we try and tailor to the individual needs. Currently, we have 8 patients who are at various phases of their treatment protocols receiving treatment.

Care is provided in a bright, cheerful, child-friendly environment. Although located on the inpatient pediatric unit, the outpatient area and treatment room has its own designated "clean" space on the unit.

Bev Sieker
Clinical Manager, Pediatrics
Kelowna General Hospital

Interview with Dr. Hanna Reysner

Dr. Hanna Reysner is a pediatric oncologist/hematologist and palliative care specialist who recently joined the team at Surrey Memorial Hospital Child and Youth Services in the Fraser Valley Health Authority. She has a cross appointment with the oncology program at BC Children's Hospital and provides consultative services for pediatric oncology palliative care patients. Her thoughts on palliative care for children with cancer follow.

What led you to specialize in the field of palliative care?

During my general pediatric training as well as my subspecialty training in pediatric oncology/hematology, I came across patients needing palliative care. I realized that I needed more experience and expertise to look after these patients and their families who generally have huge needs.

Tell me about your research on palliative care for pediatric oncology patients in BC.

My research is looking at where pediatric oncology patients die. I want to find out what factors influence their place of death, e.g. age, gender, ethnic background, availability of support services. The ultimate question is whether we are providing these children and their families the choice to die in their desired setting with the full support that they need.



Dr. Hanna Reysner and Cindy Stutzer

The concept of palliative care focuses more on the quality of life over the length of life. Choosing quality of life does not mean giving up on hope either.

Is there such a thing as a "good" death for a child? What would that look like?

I believe there is. The child would be comfortable and symptom free, in a place where he/she wants to be, and surrounded by the people that he/she loves and wants to be with. We need to communicate well with the child to find out his/her wishes. Children understand more than we realize and more than they may be able to articulate. Children with cancer especially, having gone through a lot of treatment, quite often are more mature than other children their age. And although it is difficult to discuss death with a child, we must do so with courage and expertise to help them feel fully supported through this journey.

What do you see as the unique needs of children with cancer and their families as they journey through the last days/weeks of their lives?

Transitioning from a curative mode to palliative care for these families is especially difficult. Sometimes parents wish for continued intensive treatment when the chance for cure is very small. How do we as health care professionals advocate for the child, while also realizing that it is the parents who have to ultimately live with the decision that they have done absolutely everything they can for their child? For children who do not have a favourable prognosis from the start, introduction of the palliative care concept at the time of diagnosis would be helpful.

Pediatric Palliative Care: Clinical and Psychosocial Care Workshop

Canuck Place Children's Hospice is offering a 2-day workshop that will include basic and advanced aspects of pediatric palliative care. This workshop is offered to all health care professionals who are caring for the palliative child.

Date: January 27 & 28, 2005
Time: 0830-1630
Place: Sutton Place Hotel, Vancouver BC
Cost: \$200
Contact: Camara Van Breemen
cvanbreemen@canuckplace.org

Register online at: www.canuckplace.org

primary caregivers (if transitioning to community-based caregivers is not feasible or desirable), consultants, or supports for the health care professionals (HCP) and/or family. Parents tell us that our continued involvement is important to them; that they feel abandoned when we are not involved.

Communication is always a challenge when many people are involved in a child's care. Our palliative care checklist, one-on-one phone calls, and care planning conference calls help the child's team plan his/her palliative care, provide information and updates, and opportunities for problem solving, consultation and support. Sometimes parents participate in the conference calls, or they convey concerns and questions through a HCP. Practical supports include the At-Home Program, BC Palliative Care Benefits Program, Nursing Support Services, as well as home care nurses and community-based palliative care teams.

Education is an essential part of providing pediatric oncology palliative care. Several members of our program have pursued further education in pediatric palliative care. Although we have had nursing education days regarding pediatric oncology palliative care, there is a large gap in professional education. Canuck Place Children's Hospice will help to fill that gap by offering a 2 day course in January (refer to advertisement on page 2 of this newsletter). We have also just initiated monthly palliative care discussion sessions at BCCH. At our first session, the room was filled with interdisciplinary members of the program to discuss the topic "To tell or not to tell: talking to children about death".

"Parenting a Dying Child" is an award-winning series of 30 pamphlets for parents developed by BCCH and Canuck Place Children's Hospice: Making Hard Decisions About Care, Symptom Management, Parenting a Dying Child, Talking About Dying, Honoring the Spirit and Caring for Your child After Death are just some of the titles from this package. They are available from the BCCH Family Resource Library (<http://www.cw.bc.ca/library/bookstore>). Information about grief and loss is available from Griefworks BC (www.griefworksbc.com), a provincial pediatric grief and loss program.

Research is an integral part of our pediatric oncology program. Although pediatric oncology palliative care research has lagged behind research aimed at cure, several members of our program are involved in research that will directly benefit children with cancer receiving palliative care, and their grieving families.

If we listen closely, children who are dying, and their families, will tell us everything we need to know to care for them: they want to be loved, to be cared for and cared about, to know that their lives have meaning and purpose, to be remembered as the special people they are. Most of all, they want the people caring for them to appreciate and celebrate their lives.

BCCA Annual Conference November 25-27, 2004 at the Westin Bayshore

Every year the BC Cancer Agency organizes a three day conference. Professional groups are given an opportunity to meet with their own program during this conference. The Pain & Symptom Management and Palliative Care Session on Friday, and the Pediatric Oncology Session on Saturday, will be of special interest to pediatricians, nurses, social workers, palliative care professionals and others involved in pediatric cancer care. The following is the agenda for these two sessions.

Friday, November 26

- 0830-0900 Palliative Care in the Pediatric Oncology Setting
~Speaker: *Dr. Leora Kuttner*
- 0900-0920 End of Life Care in BC - Healthcare Utilization by Pediatric Oncology
~Speaker: *Dr. Hanna Reysner*
- 0920-0950 Palliative Care for Pediatric Oncology in BC - Practice Guidelines & Referral Process
~Speaker: *Cindy Stutzer*
- 0950-1030 Panel Discussion
~Moderator: *Ann Syme*
~Panelists: *Dr. Leora Kuttner, Dr. Hanna Reysner, Dr. Caron Strahlendorf, Cindy Stutzer*

Saturday, November 27

- 0830-0930 Ethical Tensions: Challenges in Childhood Cancer and Research
~Speaker: *Dr. Fergall Magee*
- 0930-1000 New Advances in Pediatric Cancer Treatment
~Speaker: *Dr. Mason Bond*
- 1000-1030 Surgical Interventions for Pediatric Malignancies
~Speaker: *Dr. Geoff Blair*
- 1030-1100 BREAK
- 1100-1130 Nutrition for the Pediatric Oncology Patient
~Speaker: *Dr. Paul Rogers*
- 1130-1230 Open Forum: Partnership with the Regional Communities
~Moderators: *Denise Murray & Eleanor Shambrook*
- 1230-1330 LUNCH
- 1330-1430 Psychosocial Care in Pediatric Oncology
~Speakers: *Helga Grau & Sharon Paule*
- 1430-1500 Late Effects of Treatment in Survivors of Childhood Cancers
~Speaker: *Dr. Sheila Pritchard*
- 1500-1530 Transitioning Survivors to Adult Healthcare - A Model of Delivery
~Speaker: *Angela Pretula*
- 1530-1630 Meet the Survivors: Panel of Teenagers and Young Adults
~Panelists: *Shaun Evans, Rosalie Gosling, Meghan Jewell, Rob St. Amand, Dara Lynn Walker*

Register on-line at www.bccancer.bc.ca/HPI/ACC2004

For more information

To learn more about the Provincial Pediatric Oncology/Hematology Network or to submit articles or stories to this newsletter, please contact:

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The Provincial Pediatric Oncology/Hematology Network

The Network is an interdisciplinary organization whose goal is to ensure appropriate diagnosis, management, follow-up, and end-of-life care for pediatric patients with malignancies and blood disorders. The Network supports community hospitals and practitioners and develops partnerships with other health facilities to enable seamless and integrated care for patients and families on treatment and off treatment. It will further develop and enhance the research programs of basic, translational, and clinical research to better childhood cancer control and improve outcomes for these patients and their families.

Steering Committee Chairs

Dr. Paul Rogers
604-875-2345 ext 7839
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Barbara Poole
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A Parent's Story

Our eight-year old son, Conor, had a Stage II Wilms Tumour with favourable pathology. Most of our drama was in the three days between discovery, waiting for an ICU bed, and surgery. How someone removes a tumour the size of a football without breaking it or damaging the lifelines draped over it will always be one of the seven wonders of our world. We just wanted it out of him in the worst way.

He is now nearing the two-year milestone of being in remission and the numbers look very, very good (even without prayer). Since our drama began, we've had only good news and wonderful care on the health front

and have met some amazing people who likewise find themselves on this strange journey in what one parent-writer has called "the continent of cancer"¹.

~ Norman Klassen



Conor Klassen and his father, Norman

¹Wilson A. The continent of cancer. CMAJ 2000; 163(12): 1620-1.

Teen Adventures / Spirit Quest 2004

In 2004, the teens once again enjoyed an adventure-filled year:

- Dog Sled Ski-Doo Adventure - Wells Gray Provincial Park
- Tall Ship Adventure - Gulf Islands
- Day Sailing on "The Flash" 52' racing sailboat
- Kayaking and Zip Trekking - Whistler, Blackcomb
- Horseback Riding, White Water Rafting - Wells Gray Park
- Kayak Adventure - Gulf Islands
- White Water Raft Adventure - Thompson and Fraser Rivers

For more information about teen activities for 2005, please contact Dan Mornar at dmornar@cw.bc.ca or (604) 875-2345 extension 6477.



The International Society of Pediatric Oncology (SIOP)

2005 Annual Congress will be held in Vancouver, BC, from September 21-24, 2005. Please visit the SIOP website (www.siop.nl/siop2005) for more information.